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Polio Regina Incorporated

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Have a Great Summer

My Polio Story

Carole Tiefenbach is president of Polio Regina. Her hard work and enthusiasm is an inspiration to all of us. She has been a member since 1992. The following is Carole Tiefenbach's Polio Story.

Carole Tiefenbach

I was born in the St. Boniface hospital in Winnipeg, Manitoba. My mother and father ran a boarding home but I only remember slightly, the very old man, by the name of Mr. Porteous who stayed with us. I remember him because when I set our boarding home on fire (playing with an electric heater and folded paper planes), it was his room that my younger brother and I ran up to when we were so frightened by the fire! He lived on the third floor, no less! My very brave and dear mother awoke, smelled the smoke and hollered for us, and I guess Mr. Porteous hollered back, "they are both under my bed!!!" My Mom quickly ran up the stairs amid all that smoke and rescued us!

We all ended up in the St. Boniface hospital with smoke inhalation and my dear Mom had our picture in the Winnipeg Tribune under the title, "Brave Mom rescues tots from burning home!" You can bet, to this day, we were always grateful to her for that.

Just before that horrendous fire, I contacted the worst case of measles, one bout after another, Red and German and supposedly Black measles. (I have never heard of Black measles but that's what my Mom was told at the time.) The extreme high fever may have destroyed nerves in my ears, thus my hearing problem, so I have been told.

My Mom and Dad divorced shortly after and my Mom met up with my stepfather a little later and off we went to a small farming community in Geysir, MB, east of Arborg, MB. That was in 1950. I started school the following year and in the year of `52, I contacted polio. I remember walking home from school, (I REALLY did have three miles to walk!!!), but I collapsed about an eighth of a mile from the

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My Polio Story - Carole Tiefenbach continued

school. As I lay on the side of the highway, my younger brother, he might have been five at the time, walked home all that way and told our Mom that I couldn't walk and was lying on the road. My stepfather came to pick me up by horseback. I never saw a doctor. We didn't have the money for that. I remember my Mom crying while she carried me to the bathroom, wondering why I couldn't walk. My legs were paralyzed for seven months, but I could still roll off the couch to pet the family 'farm' dog, that was never allowed in the house, never mind sleep on the couch! I got caught as most kids do and I got a whacking from my stepfather. I learned to crawl with incredible arm strength to go visit Pal, the dog, out in his territory, outside on the straw bed. I must have really liked that dog because he was really my 'pal'. The days were so long and lonely. My Mom was always busy with the farm work, a huge garden, plus the usual housework, cooking and looking after the three other siblings at home. In later years, she had three more children.

My nature is to move around and move around I did, until I finally could slowly start standing up to gradual walking as I slowly got stronger and better each day. It took quite a while!! That was a happy day when I returned to school for a Valentine's party. I hadn't been to school since the end of June! I soon forgot all about my polio ordeal; having no noticeable side effects, I carried on as a normal child.

Yes, I still was told I had to walk to school, which I did, with my little brother, Brian, but in those days, we often took a ride with people who stopped to ask us if we would like a ride! Would we?? You bet! I always had very tired legs but after a rest, I could carry on. I excelled in school and sports, high jump, 'of all things', baseball, hockey and anything I felt like participating in. I loved working hard and having fun at the same time.

When I was 15 years old, I started to work at a bakery that was right across Lake Winnipeg from where we lived. I worked my butt off, at that new job, even on my days off I did laundry for the whole staff because I loved the soft water at Victoria Beach! I always loved the smell of clean laundry and to this day, I still love it.

I later married the boss' son, (I guess my boss knew his son would have a hard working wife that could work in the bakery), and we had three children. I was always very exhausted, after about eight hours of work, then I would nap when the kids napped, then carry on doing what mothers do.

After 10 years I became a single mom with three children. It was the biggest challenge I ever had, but I made it. I started to work at Safeway in the bakery as a cake decorator, one week after the busy summer. I loved my children and I loved my new job! It was very difficult for a few years but things got settled down. After about 15 years I began having severe back problems eventually leading to my quitting work. Every doctor that I saw in four years would ask me if I ever had polio and I always told them about being paralysed as a child.

I moved to Regina in 1992. After about a month, I got a referral to see Dr. Mavis Matheson as my physician. After examining me, she, like other doctors before, asked me if I ever had polio. I told her that I was paralyzed for seven to eight months as a child, and right away she suggested the post-polio group. If I remember correctly, I think it might have been the Saskatoon group, but we soon had our own Polio Regina group. I have learned so much since I joined the group. It had helped me immensely. I don't always listen to my body, but most days I do.

My husband and I volunteer our time and effort with this group to try to keep the memories alive! No one can forget about this dreadful disease ever! This polio virus still is not completely eradicated and until it is, we have to keep plugging, so the younger generation will never have to deal with the after effects of polio.

All of us should be so thankful for Rotary International, for their hard work and dedication to eradicate polio, to encourage younger parents to make sure their child is vaccinated, as many are choosing not to vaccinate.

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My Polio Story - Carole Tiefenbach continued

I am very proud to be part of an organization that is teaching us how to take better care of ourselves and let others know about our support group. I know how it has helped our members and that is what a support group should do.

My life is wonderful now. I have a very kind, loving, supportive husband, Wilf, who also had polio, whom I met in this group. We certainly understand what post-polio is and how we must look after the bodies we are left with after that debilitating disease. We belong to a wonderful church, which keeps us busy and we were asked to serve a mission in Regina for the Addictions Recovery Program, which we thoroughly enjoy. Yes, we might still do a tad too much, but as long as we rest, hopefully we can keep at it for a few more years.

Message from the President

By Carole Tiefenbach

It is hard to believe that a month ago we still had many feet of snow to contend with and now it is time to start watering our perennials and shrubs! I am certainly not complaining at all. I would rather be watering, than shoveling any day! It definitely was THE WINTER NEVER TO FORGET!!

We did manage to get away for 19 days but after returning to winter, it seemed like we never went away at all. Oh well, spring has arrived and the garden centers are grateful for the wonderful weather we are now enjoying.

Our Christmas party was a fun time with approximately 35 people out for that. Our caterer was Peg's Kitchen. She cooked us a delicious turkey dinner with all the trimmings which was enjoyed by all. Thank you to Blenda Ramsay, again and again, for arranging with Broadway Terrace for our accommodations. Next year we will be looking for another venue as Broadway Terrace will be charging the residents for the use of all kinds of little detailed items. Wilf and I will look for another venue for next year's Christmas gathering.

Our group seems to be getting a bit smaller every year and that is the case for many polio organizations, as members from all over, are getting weaker and older (we all are), and not finding it any easier to get around, or out and about. We also have lost many of our members, as they have returned to Heavenly Father, with perfect bodies and no pain any more. There is always something positive to look forward too, even though it does leave us saddened when our loved ones leave.

Our friend, Barbara Gold, from Ormond Beach, Florida, is not feeling well and she has always done the newsletter. If she doesn't find anyone to take over, that newsletter will be no more. That will be sad as she always had a lot of good information for everyone to read.

Closer to home, our friend and secretary, Ivan Jorgensen, does an amazing job as a secretary and also as our 'newsletter man'! Ivan, we all thank you for all the work and time you give to the group, along with an excellent job of putting together a very informative newsletter! Thank you, again and again!

Many thanks to David and Elaine Cotcher for all the work they do as Treasurer of our group. David keeps the books right up to date and never misses a beat. Thank you both again and again...!

We will be enjoying our Spring picnic by the time you receive this newsletter, at the home of Mavis and Adam's, who so graciously offered their home for the past few years. Thank you both, Mavis and Adam, for your hospitality. Thank you again and again!!!

In closing I would like to say, how proud I am of this Polio Regina group for their loving support and contributions each and every one make. Without your support, there would be no reason for a group such as ours. May God continue to bless each and every one of you.

Wasn't This Us

A little house with three bedrooms,
One bathroom and one car on the street.
A mower that you had to push
To make the grass look neat.

At the Meetings

November 2012 – Our November meeting, which was our Christmas party, was held at the Broadway Terrace 11th floor lounge. President Carole Tiefenbach read a draft of a letter to the new mayor regarding accessibility at the Pasqua Hospital that was composed by Diane Lemon. We agreed to request a reply by February 1, 2013 and to copy the Accessibility Advisory Committee, the Canadian Paraplegic Association and DAWN (DisAbled Women's Network). President Carole Tiefenbach will sign and send it. After the meeting we all enjoyed a delicious buffet style turkey dinner with all the trimmings. We also enjoyed a relaxing time visiting with fellow members.

February 2013 – Responses to our letter to the Mayor regarding handicapped parking at the Pasqua Hospital were distributed and debated. We decided to table the issue until the next meeting when more members are in attendance. Dr. Mavis Matheson led the open forum. The subject was "Pain Medications and Their Interactions". Mavis emphasised talking to your doctor or pharmacist about the drugs you take. She gave us four web sites where we could look up possible drug interactions and she gave us several examples of possible harmful drug interactions. Her presentation is published in this issue of the PostBox.

March 2013 – Our March meeting was our annual general meeting with the election of officers. The following are the Executive Officers of Polio Regina Inc. for 2013-2014:

President – Carole Tiefenbach

Vice-President – Wilf Tiefenbach

Secretary – Ivan Jorgensen

Treasurer – David Cotcher

Phone Co-ordinator – Carole Tiefenbach

Archivist/Librarian/Web Master – Dr. Mavis Matheson

Post Box Editor – Ivan Jorgensen

There was no specific topic for the open forum; we just went around the table and everyone had a chance to discuss whatever they wished.

April 2013 - We decided to have our open forum with guest speaker Dale Orban, Manager of Security & Parking, Regina Qu'Appelle Health Region before the meeting so he wouldn't have to wait until our business meeting was over. Mr. Orban spoke to us about some of the challenges that face parking at the Regina hospitals and some of the alternatives which have been considered. We presented some of our concerns and discussed possible solutions. Darlene Stein, Executive Director, Canadian Paraplegic Association (Saskatchewan) attended the meeting as our special guest. She agreed to be our guest speaker at our September 2013 meeting. The Spring picnic will be held on May 29th at 5:00 p.m. at the home of Mavis Matheson. Carole and Wilf Tiefenbach will look after getting the food.

Future Meetings – Wednesday September 18, 2013 and Thursday October 24, 2013. Both meetings are at 3:30 p.m. in room H203 at the Wascana Rehabilitation Centre.

Polio Vaccination Workers Shot in Pakistan

In December 2012, five female Pakistani polio vaccination workers were fatally shot in a string of co-ordinated attacks - four within 20 minutes across Karachi. The fifth woman was shot and wounded in the city of Peshawar in the north-west and later died of her injuries.

No group has said it carried out the shootings, but the Taliban have issued threats against the polio drive. There has been opposition to such immunisation drives in parts of Pakistan, particularly after a fake CIA hepatitis vaccination campaign helped to locate Osama Bin Laden in 2011. Militants have kidnapped and killed foreign NGO workers in the past in an attempt to halt the immunisation drives, which they say are part of efforts to spy on them. However, the Pakistani government says it would continue to mount its effort on polio eradication.

Polio's last stand? 2012 cases

Nigeria - 97; Pakistan - 47; Afghanistan - 26
Chad - 5

Learning More About Drug Interactions

By Dr. Mavis Matheson

Talk to your doctor or pharmacist about the drugs you take. When your doctor prescribes a new drug, discuss all over the counter and prescription drugs, dietary supplements, vitamins, botanicals, minerals and herbals you take, as well as the foods you eat. Ask your pharmacist for the package insert for each prescription drug you take. The package insert provides more information about potential drug interactions.

Before taking a drug, ask your doctor or pharmacist the following questions:

- Can I take it with other drugs?
- Should I avoid certain foods, beverages or other products?
- What are possible drug interaction signs I should know about?
- How will the drug work in my body?
- Is there more information available about the drug or my condition (on the Internet or in health and medical literature)?
- Know how to take drugs safely and responsibly. Remember, the drug label will tell you:
- what the drug is used for
- how to take the drug
- how to reduce the risk of drug interactions and unwanted side effects

If you still have questions after reading the drug product label, ask your doctor or pharmacist for more information

http://www.healthline.com/druginteractions

http://www.drugdigest.org/wps/portal/ddigest and click on drug interactions tab

http://www.drugs.com/drug_interactions.html

Saskatchewan Drug Information Services (SDIS)

Telephone:1-306-966-6378 [Saskatoon] or
1-800-665-DRUG (3784)
[Saskatchewan Only]

Fax: 1-306-966-2286
Hours: 8:00 A.M. - 12 Midnight., Monday to Friday; 5:00 P.M. - 12 Midnight weekends and statutory holidays. On-line request forms may be submitted at any time.

The following are examples of the drug interactions that are contained in the above mentioned websites of a random list of drugs:

Drug List

1. Aspir-Low
2. Avodart
3. Crestor
4. Micardis
5. Xalatan

http://www.healthline.com/druginteractions

2 Drug Interactions Found

Severe

Aspir-Low+Alcohol

Side effects from Salicylates (such as Aspirin, ASA, Doan's Pills, Trilisate, or Disalcid) may get worse if you drink alcohol-containing drinks. If you have persistent stomach upset, vomit blood or what looks like coffee grounds, or have black, tarry stools, contact your health care provider immediately. Avoid alcohol containing drinks while taking aspirin. Alcohol intake should be limited even with short term use of Salicylates.

Moderate

Micardis+Alcohol

Although an interaction is possible, Ethanol (alchohol) and Antihypertensive Agents (drugs used to reduce high blood pressure) may be used together. Ethanol or alchohol-containing beverages may increase the effects of Antihypertensive Agents on your blood pressure. If the blood pressure drops too low while taking Ethanol and Antihypertensive Agents, you may become dizzy or feel faint. To limit this interaction, avoid alcohol-containing beverages while taking medicines to lower your blood pressure. Do not stand or sit up too quickly. Contact your prescriber if you have dizziness which does not go away.

Add acetaminophen

acetaminophen+Aspir-Low

Although an interaction is possible, these drugs are sometimes used together. While the combination of Acetaminophen and Salicylates is helpful to treat pain, kidney side effects are possible with high doses or long-term use. Do not take more Acetaminophen or Salicylate (such as aspirin, Trilisate, Doan's Pills, or Disalcid) than recommended and only take together for a short period of time. Do not exceed 4 g Acetaminophen/day in adults or 75 mg/kg/day in children.

Add Aleve

Aleve+Aspir-Low

Side effects including stomach upset, heartburn, nausea, vomiting, or serious side effects such as ulcers are more likely if Naproxen is given with Salicylates (examples: Aspirin, Trilisate, Doan's Pills, Dolobid, or Disalcid), especially for an extended period of time. Many non-prescription products contain Salicylates like Aspirin; closely read labels before taking any medicines with Naproxen.

Add ibuprofen

ibuprofen+Aspir-Low

Side effects including stomach upset, heartburn, nausea, vomiting, or serious side effects such as ulcers are more likely if Ibuprofen is given with salicylates (examples: Aspirin, Trilisate, Doan's Pills, Dolobid, or Disalcid), especially for an extended period of time. Ibuprofen may also decrease the beneficial effects of Aspirin in some people. Take ibuprofen either 8 hours before or 30 minutes after aspirin. Many non-prescription products contain Salicylates like Aspirin; closely read labels before taking any medicines with Ibuprofen.

http://www.drugdigest.org/wps/portal/ddigest

ASPIRIN (in Aspir-Low Tablets) may interact with IBUPROFEN (in Advil Caplets)

Ibuprofen may interfere with the heart protective effects of low-dose aspirin. Your doctor may consider using a pain relieving agent that does not interfere with these protective effects. If ibuprofen and aspirin are taken together, take ibuprofen at least one hour after taking aspirin. Also, both of these drugs can cause stomach irritation and may potentially damage the lining of the stomach. The risk of experiencing these side effects may be increased when aspirin and ibuprofen are taken at the same time. Discuss this potential interaction with your healthcare provider at your next appointment, or sooner if you think you are having problems.

This interaction is **poorly documented** and is considered **major** in severity.

Last Updated:March 2011

ASPIRIN (in Aspir-Low Tablets) may interact with NAPROXEN (in Aleve Caplets)

Naproxen may interfere with the heart protective effects of low-dose aspirin. Your doctor may consider using a pain relieving agent that does not interfere with these protective effects. If naproxen and aspirin are taken together, take naproxen at least one hour after taking aspirin. Also, both of these drugs can cause stomach irritation and may potentially damage the lining of the stomach. The risk of experiencing these side effects may be increased when aspirin and naproxen are taken at the same time. Discuss this potential interaction with your healthcare provider at your next appointment, or sooner if you think you are having problems.

This interaction is **poorly documented** and is considered **major** in severity.

Interactions between your selected drugs

http://www.drugs.com/drug_interactions.html

acetaminophen
ibuprofen
Aleve (naproxen)
Aspir 81 (aspirin)

ibuprofen ↔ aspirin

Applies to: ibuprofen, Aspir 81 (aspirin)

Talk to your doctor before using aspirin together

with ibuprofen. Frequent or regular use of ibuprofen may reduce the effectiveness of aspirin if you are taking it to prevent heart attacks or strokes. In addition, combining these medications may increase your risk of developing gastrointestinal ulcers and bleeding. You may need a dose adjustment or more frequent monitoring by your doctor to safely use both medications. Contact your doctor immediately if you develop severe abdominal pain, bloating, sudden dizziness or lightheadedness, nausea, vomiting (especially with blood), loss of appetite, and/or black, tarry stools. It is important to tell your doctor about all other medications you use, including vitamins and herbs. Do not stop using any medications without first talking to your doctor.

Switch to professional interaction data

naproxen ↔ aspirin

Applies to: Aleve (naproxen), Aspir 81 (aspirin)

Talk to your doctor before using aspirin together with naproxen. Frequent or regular use of naproxen may reduce the effectiveness of aspirin if you are taking it to prevent heart attacks or strokes. In addition, combining these medications may increase your risk of developing gastrointestinal ulcers and bleeding. You may need a dose adjustment or more frequent monitoring by your doctor to safely use both medications. Contact your doctor immediately if you develop severe abdominal pain, bloating, sudden dizziness or lightheadedness, nausea, vomiting (especially with blood), loss of appetite, and/or black, tarry stools. It is important to tell your doctor about all other medications you use, including vitamins and herbs. Do not stop using any medications without first talking to your doctor.

Wasn't This Us

We only had one TV set
And channels maybe two,
But always there was one of them
With something worth the view.

The following is reprinted with permission from Dr. Carol Vandenakker-Albanese, Associate Professor and Residency Director, Physical Medicine and Rehabilitation, UC Davis Health System.

EXERCISE GUIDELINES FOR POLIO SURVIVORS

Exercise is defined as planned, structured, and repetitive body movement. Physical activity is movement occurring during daily activities.

A therapeutic exercise program is designed for health benefit- generally to reduce pain, increase strength, increase endurance and increase the ability to do daily activities.

Not all polio weakness is due to overuse, often lack of exercise and physical activity leads to muscle wasting and cardiovascular deconditioning.

Research supports a carefully designed therapeutic exercise program for most polio survivors to enhance optimal health and function. The program should be individualized and modified if problems arise.

Important principles to follow are:

1. Start very slowly. Often 3-5 minutes is all that can be tolerated initially if muscles have not been exercised for a period of time.

2. Interval exercise, short bouts of exercise alternating with rest periods, can be very effective.

3. Progression should be slow, especially in polio-affected muscles.

4. Intensity should be low to moderate.

5. The plan should include a rotation of different types of exercise such as stretching, cardiovascular (aerobic) conditioning, strengthening, and range of motion exercises.

6. Pacing should be incorporated into the program with at least one day of rest between strengthening exercise sessions.

7. Aquatic exercise is often ideal as the buoyancy of the water help to support weak muscles and unweight joints while providing mild resistance to muscles.

Remember it is easy to overdo in the pool because it is so much easier to move!!

8. Be aware that signs of overuse can occur 24-48 hours after too strenuous exercise or an overly active day. Symptoms of overuse indicate a need to decrease the amount of exercise or decrease the frequency of activity. The symptoms to watch for are: muscle cramps and spasms, muscle twitching, muscle pain and extreme fatigue.

REMEMBER THAT YOU CAN EXERCISE SAFELY AND IMPROVE YOUR CONDITION IF YOU APPROACH IT WITH PATIENCE AND CONSISTENCY!!

What Having Had Polio Causes, Might Cause and Does Not Cause

Marny K. Eulberg, MD, Family Practice, Denver, Colorado

Introduction: As time has elapsed since the major poliomyelitis epidemics ended, following the widespread introduction of the polio vaccines, persons affected by polio, their families and their healthcare providers seem to have less and less clear understanding about what symptoms are caused by polio, which are associated with polio and which are not. Many healthcare providers in practice today have had little experience or training in the care of polio survivors, and they studied the basic pathology that the poliovirus causes years ago.

Organizations, such as Post-Polio Health International, which exist to provide information to polio survivors, are frequently asked questions about various symptoms and the relationship to the acute polio. Post-polio groups and expert professionals have indicated that many individuals have been given incorrect or confusing information.

Attributing symptoms or changes in functioning to one's previous polio when the symptom is, in fact, due to a disease or condition that should be treated by an entirely different medical regime than polio/post-polio is not only not helpful but may be dangerous. Polio clinics can help with symptoms that are polio related and can help a person sort out what is and is not related to polio. The primary care physician can treat the non-polio related symptoms, and can also manage polio-related symptoms with guidance from knowledgeable post-polio professionals.

The intent of this article is to provide basic information about what the poliovirus does to the human body and to provide a general framework to guide patients, families and healthcare providers as they encounter new symptoms and try to understand them. Often a symptom can be caused by many different mechanisms and sometimes even by a combination of factors.

This article is *not* meant to be all-inclusive and list every possible cause/disease but to discuss the most common and most frequent conditions. As polio survivors age, especially as they approach the second half of their lives, other medical issues can emerge that may make it difficult to determine *exactly* what is causing what. Polio survivors should inform their healthcare providers about their prior history of polio because it can directly or indirectly affect their current medical condition.

What does the poliovirus do (pathology)?

The diseases that were called "infantile paralysis," acute poliomyelitis or acute polio encephalomyelitis, or simply "polio" were all caused by one of the three polioviruses (type 1, type 2 and type 3). The exact virus causing a person's disease can now be identified in the laboratory but each of the viruses can cause a similar pattern of disease when they infect an individual. As used here, poliovirus or virus refers to one or more of the three polioviruses.

The virus causes a "flu-like" illness with nausea/vomiting/diarrhea, a fever and perhaps a headache and muscle aches, and, in a small percentage of

individuals, varying degrees of paralysis. The majority of persons infected with the virus had only the flu-like illness, did not develop any paralysis and were thereafter immune to that virus.

Less than 5 percent of all individuals that were infected with the virus developed paralysis of muscles ranging from a few muscles to nearly all the muscles of their body; some people died as a result of the infection. The virus circulates in the cerebrospinal fluid all around the brain and up and down the spinal cord. In the spinal cord, the virus attacked the anterior horn cells (the nerve cells that go out to the muscle and tell the muscle what to do) but did not affect the nerves that go back to the spinal cord with messages about touch, pain, temperature sensation or position sense (where the body part is in space, i.e., "is my foot on the floor or in midair? Or is my foot on a flat surface or a slanted surface?")

The poliovirus primarily affected nerves leading to voluntary muscles. Those are muscles that you can control with thought, such as, "I think I'll point with my right index finger." This may include the muscles involved in taking a deep breath, in swallowing, of the face, of the trunk and abdomen and the limbs. There is lack of consensus among medical professionals about how much the poliovirus affected non-voluntary muscles such as those in the bladder or gastrointestinal tract. The poliovirus did not seem to cause permanent damage to the heart (cardiac) muscle.

What symptoms/signs are likely related to polio (primary effects)?

■ Atrophy (muscle wasting). The "skinny arm" or "skinny leg" is a result of the muscle or part of the muscle not getting the message from the nerve that it should contract or move. Related to this is the possible shortening of the limb. In a growing child, bone grows as a result of the muscle pull on it and/or weight bearing. Therefore, many who contracted polio as a growing child may have one arm or leg or foot that is shorter and smaller than the non-affected/less affected limb.

■ New weakness. In the more than 40 percent of polio survivors who develop post-polio syndrome, increasing muscle weakness in muscles previously affected or new weakness in muscles that were thought not to have been affected is one of the defining features of the condition.

■ Loss/absence of reflexes at a joint. For example, when the healthcare provider hits your knee with the reflex hammer and it does not "kick" out. But rarely, a polio survivor may have an exaggerated response or hyperactive reflex.

■ Muscle fatigue/decreased endurance. When a muscle does not have a full supply of "motor units" it may still be able to function for a limited number of repetitions but it "wears out" sooner. The person may be able to "sprint" but could not run a mile and certainly not a marathon.

■ Muscular pain. Polio survivors generally describe this as an "achy, burning or sore feeling." It is thought to be due to overuse of the muscle(s) in the area. Individuals who had acute polio when they were old enough to remember the event say it feels similar to the muscle pain that occurred with the acute polio. Others describe it differently, but polio-related muscular pain is rarely sharp and stabbing.

■ Biomechanical problems. These are problems related to abnormal positions of a limb around a joint, e.g., one leg being shorter than the other or abnormal curvature(s) of the spine. This can cause mechanical low back pain, increase the likelihood of "wear and tear" arthritis in a joint or a chronic tendonitis/bursitis or even nerve compression problems.

■ "Polio cold" leg or arm. There are several theories about what causes it, but it is real! Generally the person doesn't perceive the limb as feeling as cold as it feels when it is touched. It occurs when the environment is cold – such as in winter or in an air-conditioned room. Unless the person has other reasons such as poor arterial circulation from diabetic vascular disease or severe hardening of the arteries that causes poor blood flow in the arteries, "polio cold" leg or arm will not cause delayed healing of fractures or injuries. It is mostly an inconvenience to the individual and his/her bed partner.

■ Some problems with breathing. These include decreased ability to move enough air in and out to get ample oxygen into the lungs or to exhale enough carbon dioxide due to new respiratory muscle weakness or from residual muscle weakness from the initial polio. Medically this is called "restrictive lung disease." Problems include "remembering" to take a breath or to take enough breaths per minute. This is broadly called sleep apnea (central apnea). Paralysis of some muscles of the throat can also cause intermittent blockage of the air passages in the throat, which may also be termed sleep apnea (obstructive).

■ Certain problems with swallowing. These can cause choking while swallowing, especially thin liquids such as water, and sometimes some of the swallowed material will go into the lungs instead of down into the stomach causing a pneumonia known as aspiration pneumonia. Some people lose weight and have difficulty maintaining adequate nutrition because eating is so time consuming or difficult.

Note: Many people over age 50 have other problems unrelated to polio that can cause problems swallowing. Various tests can determine the exact cause of the dysphagia.

■ Osteoporosis/osteopenia. Weight bearing exercise is necessary for bone to become and remain strong. In persons who had paralytic polio the affected limb(s) may have bone that has less than the normal mineral (calcium) content. The terms osteoporosis and osteopenia refer to decreased amount of normal bone tissue; osteoporosis is more severe than osteopenia. These conditions can mean the bone is more "brittle" and may break more easily than normal bone. (Generalized osteoporosis/osteopenia can also occur in certain medical conditions and with increasing age and is usually not related to polio.)

What symptoms/signs may be related to polio (secondary effects)?

■ Increased wear and tear on joints including osteoarthritis, tendonitis, tendon tears, bursitis. When a person has a weak limb, the unaffected or lesser affected leg or arm does more work to compensate, and weakness from polio can lead to arthritis problems in the good limb as well. People who use their arms in place of their legs (crutch walkers, users of canes, manual wheelchair users) put more stress on the joints of the upper extremities than someone who has normal use of their legs, and this can result in damage to cartilage, tendons and ligaments in the wrists, elbows and shoulders.

■ Nerve compression. Carpal tunnel syndrome can be caused/aggravated by pressure on the heel of the hand and palm from crutches and canes or from propelling a manual wheelchair. Other nerves may also be compressed by abnormal positions of joints and of the vertebrae in the spine. Symptoms of nerve compression are usually a numbness or tingling, an "electric shock" sensation and sometimes progressive weakness in the area of the body supplied by the particular nerve that is being pinched.

■ Increased respiratory problems from increasing curvature of the spine resulting in less room for the lungs and internal organs.

■ Fatigue from increased energy expenditure. Walking with an abnormal gait, use of crutches and propelling a manual wheelchair all require more energy than unimpeded walking. For example, walking with a locked knee can use up 20 percent more energy than walking with an unlocked knee, and walking with two crutches can burn up to twice

as much energy as an nondisabled person would use walking the same distance.

■ Headaches. These can be "muscle contraction" headaches that may be caused by chronic overuse of neck muscles, unusual use of neck muscles when doing daily tasks or related to abnormal positions of the neck from muscle imbalance or scoliosis. Headaches, especially upon awakening, can be from inadequate ventilation (breathing) overnight that may be due to respiratory muscle weakness and/or sleep apnea that may or may not be connected to prior polio.

■ Emotional issues. These can include post traumatic stress disorder associated with hospitalizations and medical procedures and/or teasing by childhood peers or dysfunctional family interactions with the person who contracted polio.

What symptoms may be compounded by having had polio (tertiary effects)?

■ High blood pressure and/or coronary heart disease aggravated by weight gain and decreased exercise that were related to limitations imposed by polio.

■ Weight gain (including overweight and obesity) linked to decreased exercise/activity. Significant obesity, can, of itself, lead to obstructive sleep apnea and restrictive lung disease plus other problems including diabetes, osteoarthritis of hips and knees, etc.

■ Diabetes, in susceptible individuals, related to decreased activity and/or weight gain.

■ Skin breakdown, or pressure sores, from prolonged sitting without shifting position, from sleeping in one position due to difficulty turning in bed or from poorly fitting supportive devices (corsets, braces).

■ Situational depression associated with decreased functioning and independence.

More important than establishing the relationship between a condition and prior polio is finding a treatment or solution for the medical problem. Post-polio experts agree that in most instances the management or treatment plan for the secondary and/or tertiary problems are the same as for people who did not have polio.

What symptoms/signs are NOT related to polio?

■ Tremor of arm, leg or head especially when that body part is at rest.

■ Problems with "sense organs" – vision, hearing, taste, smell.

■ Seizures.

■ Allergies to medicines or to things in the environment.

■ Dizziness or vertigo ("the room spinning").

■ Sharp, shooting pains or severe burning pain with numbness. Generally, polio does not cause numbness, but nerve compression can result from abnormal positions around a joint or from crutch/cane walking or propelling a manual wheelchair and cause these symptoms.

■ Inability to know the position of a part of the body or where it is in space (decreased proprioception).

■ Food getting stuck in the lower esophagus (in the midchest or lower).

■ Abdominal pain or diarrhea.

■ Cancer of any kind.

■ Liver disease.

■ Kidney disease.

■ Most infectious diseases, except perhaps pneumonia in a person with a weak cough or who has swallowing problems and is "aspirating" food into their lungs.

■ Skin rashes, but unrelieved pressure on areas of the skin can skin breakdown and redness.

■ Diabetes, but weight gain and decreased activity often worsen blood sugar control in persons with other risk factors for diabetes.

■ Hardening of the arteries (atherosclerosis) in the heart, legs, neck, brain, although lifestyle changes induced by polio may increase the likelihood of developing this when added to other risk factors. ▲

Marny K. Eulberg, MD, is a polio survivor who has worn a brace for more than 30 years. She is a family physician who founded a post-polio clinic in 1985 and has seen more than 1,500 polio survivors. Eulberg was named "Colorado Family Physician of the Year" by the Colorado Academy of Family Physicians in 2005. She is a member of the PHI Board of Directors and serves as Secretary. Eulberg can be reached at Post-Polio Clinic, St. Anthony North Family Medicine Center, 8510 Bryant St., Westminster, Colorado 80031, 720-321-8180.

Wasn't This Us

Sometimes we would separate
To do things on our own,
But we knew where the others were
Without our own cell phone.

What Your Voice is Saying About You: Vocal Changes and the Late Effects of Polio

Mary Spremulli, MA, CCC-SLP, Punta Gorda, Florida, info@voiceaerobicsdvd.com

A speech-language pathologist in private practice, a clinical consultant with Passy-Muir, Inc. and a national seminar leader on medical topics, Mary Spremulli addresses how voice changes may relate to polio survivors, a topic raised frequently by PHI readers.

Why does my voice sound this way?

Over the last few years, a number of individuals with a history of polio 40 or 50 years ago have been referred to my speech pathology practice complaining of changes in their vocal function. They were often young children at the onset of their polio, so some of them are unsure if their original diagnosis was bulbar or spinal.

Now, many of them in their 60s or 70s report voice problems or changes, such as: "my voice is weaker," "my voice gives out by the end of the day," "my voice is scratchy and hoarse." Not infrequently, these changes in voice are accompanied by changes in swallowing function with associated complaints of increased "choking" when eating or drinking.

Is this related to having had polio?

In many of these instances, the change in voice can represent further weakening of the respiratory and phonatory (voice production) system. In particular, if individuals had initial bulbar polio symptoms, they have likely already spent a lifetime using some compensatory respiratory and oral-pharyngeal muscle function. This muscle function may now be further weakened due to further muscle degeneration, age-related changes, muscle disuse atrophy or vocal misuse. Separating out the causes and contributors to current voice problems can be challenging for the voice therapist or otolaryngologist.

Why should I see an Ear, Nose, and Throat Doctor (ENT)?

Any sudden change in voice function, or any change, such as hoarseness, that persists for more than a few weeks warrants an examination by an ENT. The ENT will conduct a direct visualization of your vocal folds and larynx (voice box) by passing a small scope with a camera through your nose and making sure there are no growths, such as nodules (calluses that form from misuse) or polyps (a usually benign, fluid-filled outgrowth of tissue that also may be from misuse) or tissue changes suggesting a more serious diagnosis.

A direct visualization can also confirm the contribution of acid reflux, in particular stomach acid that escapes from the top muscle of the esophagus (food pipe). This type of reflux, is also referred to as laryngopharyngeal reflux or "silent reflux," and it is often a factor causing hoarseness or other voice changes.

Patients are often surprised when the ENT prescribes anti-acid medication for their voice changes, not realizing that our anatomic design places the opening of the esophagus and the opening to the windpipe dangerously close, and the vocal folds often receive the insult of acid which may escape from the top muscle of the esophagus.

What is a voice evaluation?

Following an ENT examination, patients are typically referred to a speech-language pathologist (voice therapist), who may conduct further instrumental examination using videostroboscopy. In videostroboscopy, a rigid scope with a camera attachment is placed through the mouth to visualize the larynx and evaluate the dynamic movement of the vocal folds.

The voice therapist will also perform a clinical evaluation of vocal function. This exam involves taking a thorough history that includes questions about how you use your voice throughout the day, medication use that may be affecting your voice – particularly inhalers and steroids – as well as any

surgery you may have had on your throat or any tubes placed down your throat during surgery or in an emergency to maintain ventilation. Measurements of pitch, vocal intensity and voice duration are obtained, as well as observations of your respiratory patterns.

In addition to this history and perceptual data, the voice therapist will observe how you use your breath support and voice during conversational speech. Behaviors that can harm the vocal folds, such as frequent throat clearing or coughing, will also be noted as these common habits over time can injure the vocal folds. You will likely also be asked about hearing, since a decline in hearing may cause difficulty in your ability to accurately judge vocal intensity in your own voice or others.

Although not directly related to voice production, the vocal folds' position at the opening of the windpipe also makes them gatekeepers against foreign bodies entering into the upper airway. Therefore, you will be asked about any problems you may be having with choking or coughing when eating or drinking. These symptoms may also be an indication that the sensation of the larynx or function of the vocal folds have declined in some way, permitting food or liquid to now enter your upper airway. A separate swallowing evaluation may be recommended

Can voice therapy help?

Once an accurate diagnosis of your voice problem is made, treatment will likely be a combination of medical and therapeutic management. Problems requiring further medical treatment will be handled by the ENT. These may include medications to treat acid reflux, thin/thick mucus/secretions or to reduce post-nasal drainage. More serious problems, such as polyps, may require surgery.

The voice therapist will focus on vocal hygiene, which includes modification of environmental factors that may be serving as irritants to the larynx and vocal folds, instruction in methods to eliminate throat clearing and other abusive habits, and encouraging improved hydration through water intake and/or steam.

Then, much like a music teacher, the remainder of voice treatment will focus on improving functional use of your voice instrument. In the case of someone with poor diaphragmatic breathing and respiratory muscle use due to polio and post-polio symptoms, a modified respiratory muscle training program may be recommended.

Relaxation techniques and methods to reduce muscle straining in the neck muscles and larynx may be demonstrated. Use of optimal pitch and posture and techniques for improving loudness without straining will all be emphasized. Voice treatment may be offered for six to eight visits, with development of a home exercise program to encourage strengthening of the system, preservation of muscle function and maintenance of any improvement achieved. For individuals with voice changes from PPS, conservation techniques, including use of personal voice amplification devices may also be beneficial.

Our larynx is a rather amazing organ. Our ability to use its shared functions of breathing, digestion and voice production make it clearly one of our uniquely human gifts. Throughout our lives, our voice mirrors physical growth and other body changes. It conveys our physical and emotional health, and at times, it inspires poetry.

Mary Spremulli, MA, CCC-SLP, is the author of Voice Aerobics DVD, a three-part voice and exercise workout, Voice Aerobics Grand Slam™ and Voice Aerobics CD Songbirds™, speech and vocal exercise set to music (www.voiceaerobicsdvd.com). A speech-language pathologist in private practice, she leads national seminars on medical topics and serves as a clinical consultant with Passy Muir, Inc. (www.passy-muir.com), manufacturer of tracheostomy and ventilator swallowing and speaking valves.

Wasn't This Us

Store-bought snacks were rare because
My mother liked to cook
And nothing can compare to snacks
In Betty Crocker's book.

If you are a polio survivor – read this -- from the Canada Revenue Agency General Income Tax and Benefit Guide 2012

❖ Line 316 - Disability amount (for self)

To claim this amount, you must have had a severe and prolonged impairment in physical or mental functions during 2012. An impairment is prolonged if it has lasted, or is expected to last, for a continuous period of at least 12 months. You may be able to claim $7,546 if a qualified practitioner certifies, on Form **T2201, *Disability Tax Credit Certificate,*** that you meet certain conditions. To view your disability tax credit information, go to www.cra.gc.ca/myaccount.

For more information, see Guide RC4064, *Medical and Disability-Related Information.*

How to claim

- If this is a new claim for this amount, you must submit a completed (including Part A) Form T2201, *Disability Tax Credit Certificate,* certified by a qualified practitioner or your claim will be delayed. We will review your claim before we assess your return to determine if you qualify.
- If you qualified for this amount for 2011 and you still meet the eligibility requirements in 2012, you can claim this amount without sending us a new Form T2201.
- However, you must send us one if the previous period of approval has ended before 2012, or we ask you to.
- If you were 18 years of age or older at the end of the year, claim $7,546. Otherwise, complete the chart for line 316 on the federal worksheet in the forms book.

❖*Tax Tips

You may be able to transfer all or part of your disability amount (and, if it applies, the supplement) to your spouse or common-law partner (who would claim it on line 326) or to another supporting person (who would claim it on line 318).

You may be able to claim all or part of the disability amount (and, if it applies, the supplement) transferred from your spouse or common-law partner on line 326 or from another dependant on line 318.

Also, you may be able to claim a working income tax benefit disability supplement See line 453.

If you are unsure if you qualify contact CRA or a qualified tax expert.

You Are Invited

Polio Regina is inviting people who have had poliomyelitis and are now experiencing new symptoms such as fatigue, muscle weakness and cold intolerance, to join our self-help support group to learn how they can cope with post polio syndrome. Spouses and partners of polio survivors are also welcome. Polio Regina Inc. was formed to help people from southern Saskatchewan.

Our Objectives:

- To develop, promote and increase awareness of Post Polio Syndrome.
- To disseminate information concerning research and treatment pertaining to Post Polio Syndrome.
- To provide support to survivors of polio, other than financial aid.

Where to meet

Our Polio Regina group meets in room H203 at the Wascana Rehabilitation Centre 2180-23rd. Ave., Regina, SK. Enter the main doors of the Wascana Rehabilitation Centre and turn left and take the elevator that is across from the information desk. Push button "2" (not 2R) on the elevator. When you leave the elevator turn left and go past the information desk, through a recreation area, past the pool table to room H203 which is the first meeting room. Our group should be in there.

There are no meetings in January, June, July, August or December. The following are the dates of our 2013 meetings: Wednesday, September 18 and Thrusday, October 24. All meetings are at 3:30 p.m. We usually have our Spring Picnic in May at a private residence and our Christmas Party in November at a different location.

Web Site:

Check out our website for more information on Polio Regina and links to other useful related information at:

http://nonprofits.accesscomm.ca/polio/

or you can just Google **Polio Regina**.

Our email address is: polio@accesscomm.ca

Disclaimer

Information published in the Polio PostBox may not represent the opinion of Polio Regina. It is not to be regarded as Polio Regina's endorsement of treatment, products or individuals. If you have or suspect you may have a health problem, please consult your health care professional.

MEMBERSHIP APPLICATION POLIO REGINA Inc.

Name _____

Active ( ) if you had polio Associate ( ) New ( ) Renewal ( )

Address _____

_____

_____

Postal Code _____ Phone: _____

Annual membership fee: (Jan.- Dec.)

$10 Single; $15 family $_____

My donation to Polio Regina Inc.:* $_____

Total $_____

(If you require sponsorship for your fee, inform our membership chairman)

Please make cheque payable to: **Polio Regina Inc.** and mail this application form and cheque to:
Polio Regina Inc., 825 McDonald St. Regina, Sk. S4N 2X5
*(Official receipt of donation for income tax purposes will be mailed.)

Christmas Party 2012

Our 2012 Christmas Party, was held at the Broadway Terrace 11th floor lounge on November 27th. We all enjoyed a delicious buffet style turkey dinner with all the trimmings. We also enjoyed a relaxing time visiting with fellow members.