Summer 2019

POLIO POSTBOX

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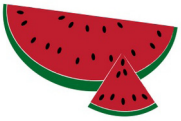
Enjoy Your Summer



My Polio Story

Carol and Ernie McClintock are loyal members of Polio Regina, always adding useful comments at our meetings. Here is Carol McClintock's Polio Story.

Carol McClintock

My story began in the fall of 1950 in Melfort, Sask.

I lived there with my parents and younger sister Lynne, who was never affected by the polio virus, but unfortunately developed MS in her early thirties; she was a quadriplegic the last ten years of her life and we lost her in 2009.

Personally, I do not remember a lot of my polio illness at the beginning, but I will try to state what I do recall.

I was 10 years old and in Grade 6. I do remember being in school, getting a bad headache, sore neck and I couldn't move my head. My teacher sent me home and from that day on it was my parents who looked after me.

I developed an extremely high fever, so my parents called our local Dr. Levitt and he came to our home. He was pretty positive that I had the polio virus as there were a number of other cases in town. Melfort Union Hospital didn't have the facilities to look after any polio sufferers so most were air-ambulanced to hospitals in Saskatoon. My fever got so extreme I was delirious so the doctor arranged for me to be air-ambulanced to Regina. My grandparents lived just outside the city at Zehner and so being that family were close by was the reason I was being flown to Regina. The day I was to be flown to Regina, the doctor came to our home and was going to drive me to the small airport in his car as there were no ambulances in Melfort at that time. He checked my condition and my fever had broken so the air ambulance was cancelled.

I was never hospitalized for my polio at any time. My parents were my only caregivers. My Dad did multi hours of massaging my neck, shoulders and left leg. I did try to get out of bed to walk but I couldn't. This was only for a temporary time and my walking

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ability returned. My mother would prop me up in bed with lots of reading material and jigsaw puzzles – to this day, my IPad and I are great friends for the reads and puzzles.

The summer after my polio virus, I came to Regina and lived with family friends so I could go to the Geriatric Centre which is now the Wascana Hospital. I would be picked up by the "bunny bus" every day and get physiotherapy treatment. It was there that I was diagnosed as having had acute poliomyelitis.

I completed my schooling in Melfort, then spent a year in Moose Jaw as a student in psychiatric nursing. I returned to Melfort and worked as a nurse's aide at the Union Hospital until October of 1960 when we were married. We settled in Regina and still call it our home after 59 years.

I worked at the Geriatric Centre as a nurse's aide for four years. Then the call of "motherhood" came and I became a stay-at-home Mom to five children over the next twelve years. I had a day care out of our home for twenty years and seven years as a home stay parent to ESL students attending University. I retired in 2010 after spending ten years clerking at Hill Avenue Drugs.

I really can't say when I started noticing the PPS other than my neck, shoulders and left knee were always most bothersome. My greatest help over the years was from my massage therapist, Darren Liski.

I had my left knee replaced in 2010 and in 2016 major neck surgery as I had neck discs pressing on my spinal cord. Dr. Ekong made me more bionic with putting a rod, plates, screws and fused my neck. My biggest problem now is that my balance is getting much worse and I never know when I could fall. A broken foot, hand and concussion in the past year and a half have made me a lot more cautious.

I have found the afternoon snooze beneficial – also very habitual. But I continue to keep my fingers busy with knitting, crocheting and some sewing.

Our family of the once five children has grown now to our being blessed with 16 grandchildren. They are spread all over the world and thanks to my IPad we can talk and see them frequently. Our travels have taken us twice to Australia and once to Korea. We have taken a couple of bus trips through CAA – Ernie loved seeing the Blue Jays play in Seattle.

Personally, I must say that as I sit at our polio gatherings and witness what other survivors have endured and visibly still have to endure, I feel so blessed that I am able to live my years more physically fit than others.

My advice for other survivors is to be so grateful that we all survived that horrible disease. Rest often!

Message from the President

Carole Tiefenbach

Has summer really arrived? We think it might have peaked its head around the corner, so now what to do when your body doesn't want to co-operate?

After 8 weeks away this past February and March, not basking in any sun, as we didn't seem to find any, we will start out wandering around the plant nurseries and local stores that sell anything green. It is so much fun to buy plants, but, not so fun to actually plant them! Everything gets to be a bit more achy and stiff when the bending and kneeling starts while planting. First thoughts, time to get a condo, as per usual, every year that is what we think of. AND we know it is time! Our bodies will only get worse as we continue our day to day activities.

Other than worry about our aging bodies, there are so many things, places and people to be grateful for! We are grateful for massage therapists, physio therapists, podiatrists, dentists, surgeons, and all doctors in general. We are grateful to still be walking. We are grateful for our home and all that we have. We are grateful for precious friends who can no longer drive or be in their own homes. We are grateful for our friends who volunteer endlessly with our Post-Polio group; Our secretary, Ivan Jorgensen, who does an amazing job, (I remember, way back, when he took over from our dear friend, Fred Ramsay, who has since passed unto the other side), and his dear wife, Blenda, (who now resides at Harbor Landing Village) who both worked so diligently putting the PostBox together for so many years. They built the foundation

of a much needed support group. Ivan also works tirelessly at finding articles to put in our newsletters, writes up the minutes, reports and makes sure we get an interesting newsletter to all who cannot attend our meetings.

Our treasurer, David Cotcher, who also is constantly finding useful info for the benefit of our group of survivors, keeping our books in order and does an amazing job at being one of the best treasurers of all time! He keeps us on our toes!

Peter Huang who is our web master and archivist, also does a great job at keeping things updated on the website. The biggest THANK YOU to all of you for doing what you do. Also, Diane Lemon, who is constantly finding interesting people to give a bit of their time, to inform us all of different methods of self-care and help that is available in our community. There are so many that have contributed their time and effort into building our support group.

For all of those who have served on the executive since we first got rolling, a great BIG thank you to all of you as well. Without all of this volunteer work, our club would not exist!

We feel honored to serve as your president and vice president and we thank you for your vote of confidence.

To each and every one of you, we love you, honor and respect you, for all that you have encountered with this insidious disease that we can honestly say, we beat it, because we are still here!

Enjoy your summer days, even though it seems way too short a time!

Love and warm regards from Carole and Wilf

At the Meetings

November 2018 – We held our annual Christmas turkey dinner with all the trimmings at Nicky's Café. The dinner included socializing and sharing experiences and was enjoyed by everyone.

March 2019 – At our Annual General Meeting Treasurer David Cotcher presented the annual financial statements for 2018 with comparative figures for 2017.

Election of executive officers for 2019 -2020.

The following are the Executive Officers of Polio Regina Inc. for 2019-2020:

President – Carole Tiefenbach

Vice-President – Wilf Tiefenbach

Secretary – Ivan Jorgensen

Treasurer – David Cotcher

Phone Co-ordinator – Carole Tiefenbach

Web Master – Peter Huang

Post Box Editor – Ivan Jorgensen

Directors – Blenda Ramsay, Diane Lemon

Diane Lemon spoke about some articles that she had read:

An article in The Leader Post about a woman in Quebec who has Post-Polio Syndrome who was denied assisted suicide.

Polio Manitoba is pressuring School Boards for vaccinations.

A play produced and performed in Newfoundland was seen by an American theatre director from San Francisco who requested for it to be performed in USA. The request was denied with the reason given that it did not meet the cultural requirements. The play was about growing up as a disabled person in rural Newfoundland.

An ad for Simpli Dental which offers general dentistry for 10-50% less than the 2019 College of Dental Surgeons of Saskatchewan suggested fee.

Open Forum: David Cotcher introduced for Tom Anderson who is a community respiratory therapist in the Regina region as our Open Forum speaker. He spoke about various respiratory problems,

testing, equipment, exercise, home visits and therapists' involvement in the community as well as answering numerous questions. A summary of Tom's presentation is included in this issue.

April 2019: Ivan Jorgensen read an email from Murray Grant about a stamp issued with Elsie MacGill on it. Her story is published later in this issue.

Ivan read an email from Jim Allonby about his knee replacement which is included later in this issue.

Location and times of future meetings: We decided that we continue to hold the meetings at Nicky's Café. The fall meetings will be Thursday, September 26th and Thursday, October 24th, both at 3:30 p.m. We tentatively set November 28th as the date for our Christmas meeting.

Open Forum: We each spoke about how we have been doing over the last year which included: vacations, family, kitchen accidents, getting weaker, and still getting around despite challenges. As we are getting older we are getting weaker and some of us are having great difficulty getting around but everyone is looking forward to summer.

Respiratory Presentation

by Tom Anderson, RRT
Respiratory Therapist with the Saskatchewan Health Authority

Breathing is something many of us take for granted. We breathe 17,000 times in a day, and for most of that we aren't thinking about it at all. For some people, though, breathing is not so easy, and Respiratory Therapists are an allied health profession whose job it is to help those people.

I have been a respiratory therapist for 7 years, working for most of that at Regina General Hospital, but recently I made a move to Primary Health Care in the community. In the hospital, my job was very diverse. I worked in the Adult Intensive Care Units, in the Emergency Department, on the hospital wards, and in the Neonatal Intensive Care Unit. If you were in any of those places, and had a breathing problem, I was there to help you.

In Primary Health Care, my job had 3 main pieces. Firstly, I did home visits for people with breathing difficulties, whether that was helping them figure out their inhaled medications, or doing checks on their home ventilator. Second, I did breathing tests at family physicians' offices to help them diagnose Chronic Obstructive Pulmonary Disease or Asthma. Finally, I ran the COPD rehab program that takes place at the Northwest Leisure Centre. COPD rehab is a program that teaches people with COPD about their disease, and gives them the opportunity to do some light, structured exercise which has been shown to improve the disease.

Within Primary Health Care, there is a sister program to respiratory therapy that I can't speak highly enough about. Senior's House Calls is a program that runs from 6am to 11pm, every day. They have a Nurse Practitioner, a Paramedic, and Pharmacist on staff. If you've ever started to feel sick, but when you call your family physician, they can't get you in for a week or two, SHC was developed for you. When you call them, they will book an appointment for one of their staff to come out and visit you within 48 hours. Because there is a nurse practitioner on staff, they can order tests and medications, draw blood work, do ECGs and more. The program was designed for people over 65 years old, or for those who have trouble for any reason getting out of the house. It's important to keep in mind, though, that if you're having a medical emergency, you need to call 9-1-1.

With my work at the hospital and in the community, one of the most common conditions I ran into was Obstructive Sleep Apnea. It is a common, underdiagnosed sleep disorder, in which your snoring is so severe that you stop breathing during sleep. It is treated with a machine called a CPAP that uses pressure to open up your airways and allow you to keep breathing and get a good night's sleep. You should talk to your doctor about obstructive sleep apnea if someone has told you that you snore very loudly, if someone has ever seen you stop breathing in your sleep, or if you don't feel rested when you wake up in the morning.

If you have any question about any of the respiratory therapy programs in the community, or would like to speak to the Senior's House Calls team, you can call 306 766-6280.

Elsie MacGill Stamp

The following is an email from our member, Murray Grant, about his relative Elsie MacGill the "Queen of the Hurricanes"

Canada Post has issued a new series of stamps on "Canadians in Flight" which includes Elsie MacGill, my mother's cousin. The stamps are sold in booklets of 10 stamps = two of each of five separate stamps with descriptions of each.

As boys in Toronto early in WWII, our family would see Elsie and her husband when she visited the city, gathering at the home of an uncle. I wrote the attached stories for our POLIO REGINA newsletter.... Cheers!!!

Murray

"Queen of the Hurricanes" was a victim of polio

by R. Murray Grant

Elsie" MacGill [1905-1980] was famous in a lot of ways. She was "the Queen of the Hurricanes" – an aeronautical engineer during World War II who helped make Canada a powerhouse of airplane construction during her years at Canada Car and Foundry in Fort William, Ontario.

Elizabeth Muriel Gregory MacGill was born in Vancouver, daughter of James Henry MacGill, a prominent Vancouver lawyer, and Helen Gregory* MacGill, British Columbia's first woman judge. Her mother was an advocate of women's suffrage and influenced Elsie's decision to study engineering.

Elsie became the first Canadian woman to graduate with an electrical engineering degree from the University of Toronto in 1927. Then in 1929, she was the first woman to graduate with a masters degree in aeronautical engineering.

> *Just before graduating she was struck by polio and wrote her final exams from a hospital bed. Told she would spend the rest of her life in a wheelchair, she refused to accept that possibility and forced herself to learn to walk with two strong metal canes.*

In 1934, she started work at Fairchild Aircraft's Canadian operations in Montreal, as assistant engineer. In 1938, she was the first woman elected to corporate membership in the Engineering Institute of Canada.

Later that year she was hired as chief aeronautical engineer at Canada Car and Foundry, where she designed a new trainer, the Maple Leaf Trainer II. It was designed and first built in Ft. William (now Thunder Bay) factories. At the time Ft. William did not even have a road connection to the rest of Canada, served entirely by rail and boats on Lake Superior.

Things soon changed when the factory was selected to build the Hawker Hurricane for the RAF, and quickly expanded from about 500 workers to 4,500 by war's end, half of them women. For much of the war her primary task was to streamline operations in the construction of the Hawker Hurricane, eventually producing almost 1,500 of them by 1943 when production ended.

Her legs were never strong enough to operate her airplanes, so she flew in the second seat on every flight test.

** It was the Gregory family that had a link to my grandmother, Josephine van Felson Weir of Winnipeg. The van Felsons were among those arriving in Quebec as early as 1759.*

Microsoft co-founder pays $3 million for a Hurricane

by Randy Boswell of CanWest News Service

A rare piece of Canadian aviation history has been transformed from a 65-year-old wreck into a fully restored flying machine and sold for a whopping $3 million Cdn to Microsoft billionaire and vintage aircraft buff Paul Allen.

The 1941 Hawker Hurricane, one of about 1,500 of the fighter planes built at a Canadian factory during the Second World War, took to the skies in Britain last month after years of painstaking reconstruction.

There are only a handful of airworthy Hawker Hurricanes left in the world, and the latest one is bound for Allen's Seattle-area Flying Heritage Collection, which will eventually house dozens of operational aircraft from the 1939-45 war.

The Hawker Hurricane was the Allied workhorse during the Battle of Britain, hailed as that nation's saviour from the Luftwaffe's devastating air attacks that nearly won Nazi Germany the war.

Though built mainly in Britain, Hurricanes were also shipped from a factory in Thunder Bay, Ont., that employed hundreds of women and became a showcase of Canadian wartime production.

The Canadian Car and Foundry Company, a successful maker of railway boxcars, was transformed into an aircraft manufacturing operation under the direction of the legendary Elsie MacGill, a 35-year-old engineer who was dubbed "Queen of the Hurricanes" in morale-boosting comic books.

More reliable and effective even than the famed Spitfire, Hurricanes used in the Battle of Britain shot down more enemy aircraft than all other defences combined.

In Canada, Hawker Hurricanes were flown for training and patrolling the coast.

Allen, who co-founded Microsoft Corp. with Bill Gates, was expected to take possession of the Hawker Hurricane in April.

Knee Surgery

by Jim Allonby

The following is an email from Jim Allonby about his knee surgery and anesthesia.

Greetings!

I went into pre-op, April 5th, 2019, with a copy of "THE KNIFE IS NOT SO ROUGH IF . . ." by Richard Bruno in hand.

I pointed out sections of the article to the nurses and especially the anesthesiologist. I said that the last time I had surgery the anesthesiologist said he would treat be like an MS patient, and not have a 'back pack' (spinal).

I made sure I had the article with me the morning of the surgery (April 12th, 2019). I wasn't seeing the anesthesiologist until I was wheeled into the operating room but the nurse photocopied the section about anesthesia and I watched him read the entire article and then I stressed to him that I should be treated as an MS patient without a back pack (spinal).

Anyway, I had a unicompartmental (half) knee replacement done on my good (non-polio) knee. Everything went along without a hitch. Pain is a lot less as the kneecap doesn't have to be dislocated. Recovery time is also supposed to be less.

I'm getting out today (April 24th, 2019). I had to stay a few extra days as I couldn't go home until I could climb 24 stairs (bedroom is on the 2nd floor). I managed 15 stairs in physio yesterday. Also the pain has disappeared and staples come out on Friday (April 26, 2019)

I hope this will help anyone who has surgery coming up.

Thanx, Jim Allonby

Editor`s Note:

I asked Dr. Bruno where I could get a copy of "The Knife Is Not So Rough If..." since I couldn't find it on his website. The following was his reply:

Ivan that article was the original that got me started writing the extensive document that is on our website under surgery and anesthesia at postpolioinfo.com. Everything you need to know is a new article which is being constantly updated.

https://www.papolionetwork.org/-anesthesia-warning.html

is a direct link to a page which contains all the information and links to other sources. The following pages are articles by Dr. Bruno on surgery and anesthesia as well as pre-op checklists.

Preventing Complications in Polio Survivors Undergoing Surgery (or) Receiving Anesthesia

Post-Polio Sequelae Monograph Series.NY: random harvest, 2016.

Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education
www.postpolioinfo.com

Unfortunately, only a handful of specialists treat Post-Polio Sequelae (PPS) - the unexpected and often disabling fatigue, muscle weakness, joint pain, cold intolerance, swallowing, sleep and breathing problems - occurring in America's estimated 1 million polio survivors (40 years after their acute polio).1,2 However, all medical professionals need to be familiar with the neurological damage done by the original poliovirus infection that today causes unnecessary discomfort, excessive physical pain and occasionally serious complications after surgery. This is a brief overview to inform patients and professionals about the cause and prevention of complications in polio survivors undergoing surgery.

PRE-OPERATIVE PREPARATION

The pre-operative period is the most important, since it is when polio survivors must establish communication with the surgical team. After the second opinion and a polio survivor's decision to have surgery, the patient needs to ask the surgeon to read this article and the references cited. Then, surgical candidates must meet with the surgeon and anesthesiologist to discuss in detail patients' complete polio and general medical histories and the problems that will likely arise before and during surgery, in the recovery room and on the nursing floor. It is also recommended that the polio survivor meet with the Supervisor of Nursing on the floor where they will be transferred after surgery to discuss likely problems during the post-op and recovery period.

Lungs. We recommend that all polio survivors have pulmonary function studies as part of their pre-operative. This is vital for those who had bulbar polio acutely, whether or not they used a respirator or an iron lung. But, polio survivors who have (or had) neck, arm or chest muscle weakness or have swallowing problems should also have their lung function tested 3 so there will be no unpleasant surprises coming off the respirator at the end of the operation. Polio survivors with a lung capacity below 70% may need a respirator or respiratory therapy after surgery. 1 Of course, polio survivors who use a respirator during the day or at night must discuss their respirator use and maintenance in detail with their surgeon, anesthesiologist, the nursing staff, and with their own pulmonologist, before admission to the hospital.

Physical Assistance. X-rays are a normal part of pre-op testing. Because of workers compensation concerns, many hospital staff are not eager to move or lift patients. Unfortunately, X-ray and examining tables are built at heights that are convenient for the professional, not the patient. Many polio survivors cannot step on a stool to get onto a high table, or even pull themselves over onto a table from a stretcher. Thus, polio survivors must ask for help in transferring. Since most polio survivors have no experience asking for help under any circumstances, they need to find a phrase with which they are comfortable that will communicate whatever their needs are. Long explanations about having had polio or PPS or the specifics of which muscles are weak or paralyzed are not necessary. (For example, a simple "My legs (arms) are paralyzed and I can't get onto that table" or "I will need help" should suffice). This phrase may have to be repeated before the polio survivor will be assisted. If the professional replies, "Oh, I bet you can move by yourself if you try!" or "Don't expect me to lift you," an appropriate response is "I cannot get onto the table. Please ask someone else to help me or let me speak to your supervisor." A pleasant but steadfast refusal to do difficult or dangerous transfers is the polio survivor's best defense against injury before or after surgery.

ANESTHETICS

General Anesthetics. Polio survivors are exquisitely sensitive to anesthetic. It has been known for 50 years that the poliovirus damaged the area of the brain stem - called the reticular activating system (RAS) - responsible for keeping the brain awake.4, 5 Because the RAS was damaged in those who had paralytic

and non-paralytic polio, a little anesthetic goes a long way and lasts a long time. For example, the pre-operative medication used to "calm" surgical patients - sometimes Valium or Vistaril - may by itself put polio survivors to sleep for 8 hours. (Such excessive and prolonged sedation does occur when low-dose Propofol is used alone in patients undergoing invasive but nonsurgical procedures, like endoscopy.) Add to a pre-operative "calming cocktail" an intravenous anesthetic (like sodium pentothal) or a gaseous anesthetic, and polio survivors have been known to sleep for days. Propofol *is* the drug of choice for polio survivors. In addition, polio survivors with respiratory problems may have trouble clearing the gaseous anesthetics. A number of our patients have awakened from anesthetic on a respirator in I.C.U. to the frightened faces of their family, surgeon and anesthesiologist several days after surgery.

Here is the first of rule of thumb - we call "Rules of 2" – for polio survivors having surgery:

Anesthetic Rule of 2:
Polio survivors need the typical dose of anesthetic divided by 2.

This first "Rule of 2" is certainly NOT intended to dictate the dose of anesthetic, but merely to remind anesthesiologists that polio survivors need much less anesthetic than do other patients. This does not mean that a given polio survivor might require less than 1/2 the typical anesthetic dose, or that another won't need more anesthetic. As always, the dose of anesthetic must be individually adjusted (for body weight, lipid space, etc) and be adequate to keep patients under during surgery but not cause them to sleep for a week. We have found Desflurane to be the best tolerated anesthetic when used with BIZ brain wave monitoring.

Even applying the "Anesthetic Rule of 2" polio survivors may be very sedated, if not asleep, for many hours after the surgery. This is one of the reasons why same-day surgery - even for complicated dental procedures - is not advisable for polio survivors. Sleeping or excessively sedated polio survivors cannot be expected to return home and take care of themselves after same-day surgery, since surgical complications may go unnoticed and sedation-impaired coordination makes falling likely. In spite of insurance company pressure, NO POLIO SURVIVOR SHOULD HAVE SAME-DAY SURGERY except for the simplest procedures that require only a local anesthetic.

Nerve Blocks. However, there are also problems with local anesthetics that numb only one area of the body. Spinal anesthetics, like epidural or saddle blocks used for childbirth and lower body procedures, often allow surgery without the patient being asleep and are therefore more desirable for polio survivors. However, the injection of a local anesthetic near the spine results in both pain-conducting nerves and motor neurons being anesthetized. Polio survivors are very sensitive to anything that further impairs their poliovirus-damaged motor neurons and a spinal anesthetic may cause polio survivors to be paralyzed for many hours. If a spinal anesthetic is used, polio survivors cannot be expected to get up and walk after surgery. Curare-like drugs that are intended to paralyze muscles (e.g., succinylcholine) are typically used during major surgery to relax muscles that are going to be cut and make it easier for the ventilator to fill the lungs while patients are on the table. Again, any drug that interferes with muscle functioning will prevent polio survivors from walking or even moving for hours longer than it would for patients who didn't have polio.
Regardless of whether a local, spinal or general anesthetic is used, the following applies:

Post-Anesthetic Rule of 2:
Polio survivors require 2 times as long to recover from the effects of any anesthetics.

Blood and Guts. There are yet additional concerns. Polio survivors with muscle atrophy, especially in the thigh muscles, will have a smaller blood volume than would be expected for their height or weight. Therefore, bleeding during surgery may be more of a problem. Polio survivors may want to bank their own blood slowly over the course of weeks, even for procedures where excessive blood loss is not typically expected. However, since polio survivors may be significantly more fatigued and prone to faint after giving blood, relative's blood may need to be banked instead. Also, polio survivors can be sensitive to atropine-like drugs used to dry secretions during surgery. 6 Atropine-like drugs also slow the gut, and polio survivors may be excessively constipated after surgery or, in some cases, actually have their stomachs and intestines stop

moving (gastroparesis; paralytic ileus) for a period of time. These problems can be treated symptomatically as they would in someone who did not have polio.

Positioning. One overlooked problem is the positioning of the post-polio patient on the operating table. Muscle atrophy, scoliosis and spinal fusions may make certain positions problematic, especially those involving extension of the spine. Since the polio survivor is usually unconscious during positioning, there will be no report of pain that would normally warn of potential damage. A number of polio survivors have experienced severe back pain for months post-op, and even permanent traction injuries of nerves, after being placed for hours in damaging positions. It would be advisable for the patient to be awake during positioning on the table to prevent such post-op complications.

POST-OPERATIVE CARE

Cold. If the dose of anesthetic is carefully regulated, a polio survivor's first post-op experience will be waking in the recovery room. Often, polio survivors awaken from anesthetic shivering violently. Research has shown that polio survivors are extremely sensitive to cold because they have difficulty regulating their body temperature. Polio survivors' automatic (autonomic) nervous systems were damage by the poliovirus from the brain (hypothalamus) through the brain stem (reticular formation and vagal nuclei) to the spinal cord (intermediolateral columns). 4-8 Polio survivors cannot control the size of their blood vessels, since the nerves that make the smooth muscle around veins and capillaries contract were paralyzed by the poliovirus. Therefore, polio survivors' blood vessels open under anesthetic and dump the heat of their warm blood into the cold recovery room. Recovery room nurses need to know about this problem and help polio survivors stay warm. Additional blankets will help, and the surgeon can even write an order for a heated water blanket to be used in recovery.

Vomiting. Another post-op problem related to brain stem damage is vomiting. As in anyone who receives a general anesthetic, polio survivors can develop nausea and vomit. However, polio survivors are more apt to faint (have vasovagal syncope and even brief asystole's) when they attempt to vomit. 6 It is very important that post-operative emetic control be discussed with the anesthesiologist and administered before polio survivors go to the recovery room and that additional medication is written as needed in the post-op orders.

Choking. Yet another concern is difficulty swallowing as the patient is awakening. 9 Polio survivors who are aware of having swallowing problems, and sometimes in those without apparent swallowing difficulty, cannot clear secretions and may choke (or feel like they are choking) when they are lying on their backs, still half asleep, as the anesthetic is clearing. Polio survivors' secretions need to be monitored in the recovery room and they should be positioned on their side if possible so that secretions can drain.

Pain. The single most troublesome problem after surgery is pain control. A number of studies have shown that many surgical patients are under medicated for pain. Under medication is a serious problem for the post-polio patient since two research studies have shown that polio survivors are twice as sensitive to pain as those who didn't have polio. 8 Increased pain sensitivity is apparently related to poliovirus damage to endogenous opiate-secreting cells in the brain (Para ventricular hypothalamus and periaquiductal gray) and spinal cord (Lamina II of the dorsal cord). 4,8

Rule of 2 for Pain:

Polio survivors need 2 times the dose of pain medication for 2 times as long.
Polio survivors are known to be extremely stoic and are very unlikely to abuse or become dependent upon narcotics.

RECOVERY

In keeping with the "get 'em up, move 'em out" trend in medicine, there will be the tendency to get polio survivors up and walking almost immediately after surgery. This is not advisable for a number of reasons. When polio survivors reach the nursing unit, they may still be twice as sedated from the anesthetic as are other patients. Since polio survivors need a very clear head to be able to control their weakened, polio-affected muscles to stand and walk, a fuzzyheaded polio survivor is at serious risk for falling. Even if a polio

survivor's head is clear, the anesthetic or other drugs may have temporarily weakened or even paralyzed the muscles needed to stand and walk. What's worse, the surgery may have cut muscles (especially abdominal muscles) that substitute for muscles paralyzed by polio (it is often muscle substitution that actually allows polio survivors to stand and walk, even though the muscles that are typically needed to walk were permanently paralyzed). Not only will post-polio patients be unable to stand or walk, they may also be unable to even move to position themselves in bed. Polio survivors may also have low blood pressure after surgery that could itself cause lightheadedness, fainting and falls.

Rule of 2 for Recovery:
Polio survivors should stay in bed 2 times longer than other patients.

Under any circumstances, polio survivors should get up slowly, first sitting up in bed, then sitting with feet dangling, then getting into a bedside chair with assistance, then standing with assistance and finally walking with assistance and appropriate assistive devices. With the necessity of additional bed rest, anti-embolism stockings and medication to prevent blood clots may be a prudent precaution. Gentle physical therapy in bed may be advisable to maintain range of motion and for stretching, since polio survivors are prone to developing painful muscle spasms if they are not up and moving.

Rule of 2 for Length of Stay. Polio survivors need to stay in the hospital 2 times longer than other patients. While polio survivors may become deconditioned with bed rest somewhat faster than others patients, because of autonomic nervous system damage, the dangers of getting them up and walking too quickly far outweigh those of moving too slowly. Polio survivors have learned to be very aware of what their bodies can and can't do. They are the best judges of when they can move, stand and walk safely.

Nursing Care and Nurse Caring. Polio survivors often have difficulty merely being in the hospital. They may have insomnia, anxiety, and even have panic attacks. These symptoms are easy to understand when it is remembered that as young children, polio survivors were ripped away from their families and admitted to rehabilitation hospitals for months or even years. 2,10,11 Post-polio children underwent multiple surgeries and painful physical therapy, procedures administered often without explanation and certainly without their consent.

Many post-polio patients have had multiple experiences of psychological, physical and even sexual abuse at the hands of hospital staff. Questions or complaints about painful and frightening therapies were not infrequently met by staff anger or punishment. Patients report having been locked in dark closets overnight when they asked questions, spoke out or cried. Necessary nursing care could be withheld for no apparent reason. Many post-polio children were slapped and some were actually beaten with rubber truncheons by physical therapists to "motivate" them to stand up and walk. 10

It is not surprising that polio survivors can be terrified of again becoming powerless patients at the mercy of hospital staff. Nursing staff's appreciation of the childhood trauma polio survivors experienced at the hands of medical professionals, and taking a moment to actually listen and respond to the real needs of the adult post-polio patient, will go far toward making the patient feel safer and more comfortable during their stay.

RETURNING HOME

There is another "Rule of 2" when surgical patients return home:

Rule of 2 for Work:
Polio survivors need 2 times the number of days of rest at home
before they return to work or household duties.

For all of the reasons described above, the entire recovery process takes longer for polio survivors. It is not uncommon for typically overachieving, hyperactive Type A polio survivors, who were taught as children to "use it or lose it," to return to work or household duties the day after they return home from the hospital.10,11 Polio survivors must be encouraged to rest and to return to activities slowly, especially if they are somewhat deconditioned and feel weaker or more fatigued post-op. Polio survivors should ask their surgeon for a note that allows them to stay home from work twice as long as the typical patient.

POST-OP PPS? The 1985 National Survey of Polio Survivors has shown that emotional stress is the second most frequent cause of PPS (after physical overexertion).11 Certainly, there are few emotional or physical stressor more potent than surgery. So, polio survivors should expect some increase in fatigue and muscle weakness resulting from the combination of the physical and emotional effects of the surgery, anesthesia, other medications, and bed rest.

However, only a handful of post-polio patients permanently lose function after surgery. Strength or endurance lost after surgery are typically recovered. To aid recovery, gentle physical therapy may be advisable. Passive stretching, range of motion exercises and slowly increasing endurance are more valuable than muscle strengthening exercise which can actually cause muscle weakness. Especially if a polio-affected part of the body has been operated on (stomach, back, arms or legs), a physiatrist who is thoroughly knowledgeable and experienced about the care of polio survivors and PPS should be consulted before surgery so that a post-op rehabilitation plan can be in place. A short stay in a rehabilitation hospital after surgery (especially after back or leg surgery) may make polio survivors recovery safer, faster and more complete.

Polio survivors need to remember the:

Rule of 2 for Feeling Better:
Polio survivors need 2 times longer to feel "back to normal" again.

CONCLUSION

All of the "Rules of 2" are suggestions for polio survivors and the surgical team; they are *not* a substitute for specific information about the individual patient and communication among all members of the treatment team, including the patient. All polio survivors must be evaluated and managed according to their individual needs. Please take the time to read the following references so that you will be fully knowledgeable about and be able to help meet polio survivors' special needs.

REFERENCES

1) Bruno RL. Ultimate burnout: Post-polio sequelae basics. New Mobility, 1996; 7: 50-59.
2) Frick NM, Bruno RL. Post-Polio Sequelae: Physiological and psychological overview. Rehabilitation Literature, 1986; 47: 106-111.
3) Bach JR, Alba AS. Pulmonary dysfunction and sleep disorder breathing as post-polio sequelae: Evaluation and management. Orthopedics, 1991; 14: 1329-1337.
4) Bodian D. Histopathological basis of clinical findings in poliomyelitis. Am J Med. 1949; 6: 563-578.
5) Bruno RL, Frick NM, Cohen J. Polioencephalitis, stress and the etiology of Post-Polio Sequelae. Orthopedics, 1991; 14: 1269-1276.
6) Bruno RL, Frick NM. Parasympathetic abnormalities as post-polio sequelae. Archives of Physical Medicine and Rehabilitation, 1995; 76: 594.
7) Bruno RL, Johnson JC, Berman WS. Vasomotor abnormalities as Post-Polio Sequelae. Orthopedics, 1985; 8:865-869.
8) Bruno RL, Johnson JC, Berman WS. Motor and Sensory Functioning with Changing Ambient Temperature in Post-Polio Subjects. In LS Halstead and DO Wiechers (Eds.): Late Effects of Poliomyelitis. Miami: Symposia Foundation, 1985.
9) Bucholtz DW, Jones B. Post-Polio dysphagia: Alarm or caution. Orthopedics, 1991; 14: 1303-1305.
10) Bruno RL, Frick NM. The psychology of polio as prelude to Post-Polio Sequelae: Behavior modification and psychotherapy. Orthopedics, 1991; 14: 1185-1193.
11) Bruno RL, Frick NM. Stress and "Type A" behavior as precipitants of Post-Polio Sequelae. In LS Halstead and DO Wiechers (Eds.): Research and Clinical Aspects of the Late Effects of Poliomyelitis. White Plains: March of Dimes Research Foundation, 1987.

International Centre for Polio Education

POLIO SURVIVORS' PRE-OP CHECKLIST

1. Give list of articles (above) to surgeon and discuss:
    1. Pre-op lung tests with measuring of carbon dioxide.
    2. Possibly having lower blood volume and blood banking or bloodless surgery?
    3. Authorization for a longer stay in the hospital if needed.
    4. Orders for post-op anti-vomiting medication.
    5. Positioning and cushioning on the table during surgery.
    6. Orders for staying warm in the recovery room.
    7. Difficulty clearing secretions in the recovery room and on the nursing unit.
    8. **Orders for increased dose of pain medication.**
    9. Physical therapy for stretching and range of motion in hospital.
    10. Placing articles about polio in the medical chart.
2. Give list of articles to anesthesiologist and anesthetist and discuss:
    1. Any lung problems AND THAT POLIO SURVIVORS CAN RETAIN CARBON DIOXIDE.
    2. Lower dose of pre-op calming medication.
    3. **Using *lower* dose of anesthetic.**
    4. Longer-term paralysis of muscles with spinal anesthetic and curare-like drugs.
    5. Orders for post-op anti-vomiting medication.
    6. Difficulty clearing secretions in the recovery room.
3. Give list of articles to nursing supervisor and discuss:
    1. Longer-term sedation with anesthetic.
    2. Difficulty clearing secretions on the nursing unit.
    3. **Orders for increased dose of pain medication.**
    4. Needing help in moving in bed and in the room.
    5. Not standing or walking until you are fully awake and able.
    6. Anti-embolism stockings and anti-clotting medication.
4. Meet with PPS physiatrist before surgery and discuss:
    1. Post-op rehabilitation plan.
    2. Physical therapy for stretching and range of motion in hospital.
    3. Possible admission to a rehab hospital before going home.
    4. Physical therapy for walking and increasing endurance at home.

Preparing for Surgery

A Bruno Byte

From Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education

"When Seconds Count" from the American Society of Anesthesiologists

In addition to Post-Polio Anesthesia Sensitivity, be sure to tell your physician anesthesiologist about these additional issues:

- **Anesthesia Reaction**. It's important to share if you've had a bad reaction to anesthesia during previous procedures. Your physician anesthesiologist will ask detailed questions about what happened to adjust your anesthesia and prevent it from recurring.
- **Alcohol Consumption**. More than two alcoholic drinks a day can increase your risk of side effects from anesthesia as well as affect the amount of anesthesia you'll need. Your physician anesthesiologist needs to know if you drink and may request you abstain before surgery.
- **Chronic Health Issues**. Many chronic health conditions can have repercussions for anesthesia, including diabetes, heart disease, allergies, liver or kidney disease, asthma, high blood pressure, obesity and seizures or other neurological disorders.
- **Heat Stroke or Suffered a Stroke**. If you or a family member have ever had -
    - Heat stroke (a reaction to excessive heat when the body is unable to regulate its temperature) (or)
    - Suffered a Stroke tell your physician anesthesiologist. Both can increase your risk of having a severe and potentially deadly reaction to anesthesia called malignant hyperthermia, which causes muscle rigidity and a sudden high fever.
- **Marijuana Use**. Marijuana has a sedative affect and can interact with anesthesia, so it's important to tell your physician anesthesiologist if you partake, whether by eating edibles, smoking or other methods. Further, smoking marijuana holds many of the same significant risks that smoking cigarettes does.
- **Medications**. Many medications can affect anesthesia or pain management. Research shows a certain class of antidepressant can blunt the effects of some opioids. If you take it, the physician anesthesiologist may choose a different type of pain management. While some medications (such as blood pressure medications) should be continued even during surgery, others may need to be paused for a day or longer. Be sure to discuss all your medications so the physician anesthesiologist can determine the best course of action.
- **Supplements**. Like other medications, certain supplements can interact with anesthesia. Many people take ginkgo biloba to improve their memory or ginseng as an immune system booster, but both can increase the risk of bleeding. Be sure to tell your physician anesthesiologist what supplements you take and the dosage. Bring your supplements to your presurgical

appointment with your anesthesiologist, or take a picture of the list of ingredients with your phone.

- **Smoker**. Smoking damages your heart and lungs and can lead to breathing problems during or after surgery. It also increases your risk of: developing pneumonia; needing a ventilator to help you breathe after surgery; suffering a heart attack during or after surgery; and reducing blood flow, which slows healing and increases the chance of infection. For these reasons, your physician anesthesiologist will likely ask you to stop smoking at least a week or more before the procedure. (And since you'll heal faster if you don't smoke while you recover, consider taking the opportunity to quit smoking altogether.)

- **Snoring/Sleep Apnea.** If your snoring is caused by sleep apnea – in which breathing is interrupted during sleep – anesthesia is riskier because it slows breathing and increases sensitivity to side effects. Sleep apnea also can make it more difficult for you to regain consciousness after surgery. If you have sleep apnea, the physician anesthesiologist may adjust the sedative, keep you in recovery longer and prescribe non-opioid pain medications.

You should discuss these issues and any concerns you have when you talk to your anesthesiologist before surgery. For example, if you are concerned about taking opioids, your anesthesiologist can discuss alternatives. Your anesthesiologist also will ask you questions and may order tests before surgery, such as a cognitive screen to assess your mental function, especially if you are elderly. Based on the results of those tests, your concerns, the information you provide and your health, the anesthesiologist will adjust your anesthesia, pain management and directions for recovery.

To learn more about preparing for surgery, visit www.asahq.org/wscpreparingforsurgery. You also can download and print Preparing for Surgery: An Anesthesia Checklist and The Path to a Safe Surgery: Preparing for Anesthesia Begins with You to take with you to visit your anesthesiologist prior to surgery, as well as when you go to the hospital or outpatient clinic for the procedure. To learn more about the critical role physician anesthesiologists play before, during and after surgery, visit www.asahq.org/WhenSecondsCount.

The Full Article is available - https://www.asahq.org/whensecondscount/preparing-for-surgery/?fbclid=IwAR28LRosLd1K7oZD5MMJ2XwmumeAnFxPlOXNAZzBzuXQzpwf6CXgL7jn0Hc

NOTE: Post-Polio Anesthesia Sensitivity is available under "Anesthesia" in the articles section of the Encyclopedia.

The Encyclopedia of Polio and Post-Polio Sequelae

contains all of Dr. Richard Bruno's articles, monographs, commentaries, videos and "Bruno Bytes" (Q & A articles).
https://www.papolionetwork.org/encyclopedia.html

Symptom Check List
For Families and Caregivers
I am a Polio Survivor with Post-Polio Sequelae

- **EASILY SEDATED, and may be difficult to wake**
- **Can Have Difficulty BREATHING and SWALLOWING with Anesthesia**
- **HYPERSENSITIVE to PAIN and COLD.**

May Need heated blanket and Increased pain medication post-op.

Name: _____

I have these Symptoms of PPS (checked):

☐ Overwhelming Fatigue	☐ Muscle Weakness
☐ Muscle and Joint Pain	☐ Sleep Disorders
☐ Cold Intolerance	☐ Difficulty Swallowing
☐ Difficulty Breathing	☐ Sensitivity to Anesthesia

"Breathing Outcomes for Post-Poliomyelitis Syndrome (PPS)"
http://www.breathenvs.com/#!blank/n0gnd

International Centre for Polio Education
http://postpolioinfo.com/centre.php

"Post-Polio Care for our Families and Health Care Providers"

https://www.papolionetwork.org/information-for-pps-caregivers-and-providers.html

Post-Polio Health International
http://www.post-polio.org/ and
http://www.post-polio.org/edu/healthcare/index.html

"Preventing Complications in Polio Survivors Undergoing Surgery"
http://www.papolionetwork.org/-anesthesia-warning.html

Please take this information into account, when you are creating my treatment plan. I have added additional information, relating to my medical history on the back side of this page. (Allergies, Current Medications, Tests Etc.)

Signature: _____ **Date:** _____

www.papolionetwork.org Rev. 2019

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

The next two Polio Regina meetings will be held at Nicky's Café, on the corner of Eighth Avenue and Winnipeg Street, on Thursday September 26, 2019 and Thursday October 24, 2019 at 3:30 p.m. Nicky's has extra parking at the back and it is wheelchair accessible. Our Christmas Dinner tentatively will be held November 28th at 5:00 p.m. at Nicky's Café.

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.)