



Christmas 2016

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Season's Greetings



My Polio Story

Lloyd and Anne Bartel have been active members of Polio Regina since it began and were also active in The Saskatchewan Post-Polio group prior to Polio Regina. The following is Lloyd Bartel's Polio Story.

Lloyd Bartel

Lloyd was born on the farm at Drake Saskatchewan. I attended a one-room school and only spoke German, so the grade one teacher used pictures of the farm animals and equipment to teach me English. I enjoyed sports particularly track and field.



On the morning of September 17, 1949 at the age of 14, life changed when early in the morning I awoke with awful pain all over my body. After seeing the local Doctor my cousin and my father took me by car to Regina and I was admitted to the isolation wing of the General Hospital. The treatment consisted of putting hot compresses over my whole body; they were as hot as were tolerable. There was also physiotherapy to attend.

In a recent letter we discovered which was written to my father by Dr. Buschinski, he indicated both legs were involved but that the right leg was most affected. He also noted they expected people would make

good recovery from Polio. My right leg continued to be affected and I was unable to walk without the use of crutches or a long leg brace. I was in the hospital for 4 months doing physiotherapy and after release had a home program to follow.

My brother and I shared a room but neither he nor my sister contracted the poliovirus.

After returning from Regina I returned to the farm and was expected to carry my fair share of the work. I also returned to school and completed my Grade 10, since after that I would have had to attend a school with stairs; I decided that was not for me.

Working for my father on the farm had its challenges but one thing I am grateful for was his habit of having

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a nap after the noon meal. I took full advantage of this habit, as I found I easily got tired.

My life took on a new prospective when I went to Edmonton for a CPA conference, for farmers with Disabilities. It was there I met Anne and 18 months later we were married.

Anne was able to provide the information as to how I could get a referral to Wascana Rehabilitation Centre and I was fitted with a more functional brace. After consultations with Dr. White and Dr. Fink it was determined that I had post-polio syndrome.

Dianne Lemon provided us with information about a new support group which was being formed Post-Polio of Saskatchewan. I started to attend the meetings and soon found myself as one of the representatives of the Regina branch. Maurice Denzin and I would travel to Saskatoon for meeting and then report back to this group.

One thing that has always been of interest to me is music. I sang in church choirs and male voice choirs over the years. After coming to Regina I was invited to sing in the Regina Philharmonic chorus. It was a challenge to have to audition for acceptance, as that had never been part of the previous choirs. A real highlight of my time with them was being able to sing tenor and perform the Messiah at the Centre of the Arts with a full orchestra and have Ben Heppner as the guest soloist.

Another very important part of my life is being involved with a church family with a good mix of ages and solid teaching.

In recent months I had experienced more weakness and after doing Physiotherapy and participating in an exercise program and seeing no results, we discussed it with our physician as I had started taking Lipitor and found out it could have that as a side effect. He agreed I should stop taking it and I am already seeing positive results.

I feel one must pace oneself and be around folks who are positive.



Message from the Vice-President and President



We are just home two weeks now, from another wonderful trip to Utah! We have not traveled every State in the USA, but we both agree, Utah has to be the most

beautiful of all!!! Bryce Canyon and Zion National Park are totally unbelievable! The rock formations are definitely a touch of our Heavenly Father's artistic Hands. It is definitely a trip I would recommend to anyone who feels like traveling or shall I say, is able to travel still. We are grateful for every day that we can still get around and still drive to our destinations. The day will come far too soon when we cannot travel anymore.

Wilf has all the Christmas decorations up and glowing. He said it felt like he just took them down, and I agree! It does feel like Christmas was just over a little while ago. That is how fast these last 'end of the year' days go!

While we were in Park City, we went to see Gary Lewis (Jerry Lewis' son) and the Playboys! It was just an 'okay' show. The guy is 70+ years old and certainly cannot sing anymore but he put on a great show with an amazing backup band and vocalists, which, of course, were not the original band at all!! They sang a lot of the oldies which was great and Gary sang 'This Diamond Ring', and of course, with a fabulous backup, he sounded great! I found out today that my new hearing aids might have a cracked microphone and I would guess it would be from that one noisy band! They were extremely loud!! Smart people wore earplugs!!! Of course, I took my hearing aids out immediately, but I think it was too late!

Next is the planning and packing for our longer holiday in Kissimmee, Florida, in mid-January.

We are both 'injured' now, Wilf, with his left arm, me, with my right, and both about 6 weeks into our injuries. We both had silly falls again within a day of each other so it has been chiropractor, physio,

acupuncture and massage appointments for 6 weeks! We are still managing to keep up the house and do our errands and Wilf manages to go to work a few days a week yet. Grateful, again for all the professionals that help us out and get us moving again!

Last, but not least, the most important part of our message, is a huge THANK YOU to our executive: our hard working secretary, Ivan Jorgensen, who keeps such meticulous notes and puts together the most interesting newsletters, (we also know you learned that trick with some help from an awesome member whom we have lost, Fred Ramsay). (Bless his hard working soul). Our newsletters are certainly one of the best!! Thank you, Ivan! David Cotcher, our diligent treasurer, who keeps our bank account accurate at all times. David, also, is always thinking of different topics we can discuss at our meetings and comes up with some great ideas. Thank you, David! Peter Huang, our librarian and archivist who manages our web page online! Thank you, Peter!

A huge THANK YOU to every member who continues to come out to the meetings and share their stories with us and ask people in their everyday lives to come share some of their knowledge with us, so we can continue to learn and take care of our Post-Polio bodies! It is a huge help to each and everyone of us!

We wish you all, and your loved ones, another year of health and prosperity, a Blessed Christmas, to remember the Reason for the Season, and a very Happy New Year in 2017!!!

With love and warm regards,
Wilf and Carole Tiefenbach



At the Meetings

May 2016 - We were invited to take a group tour of Wintergreene Estates which is a retirement community in Regina. They offer three different lifestyles from independent apartments to assisted living with nursing care. Nine of our members attended the tour.

Our May meeting was also our annual spring picnic which was enjoyed by everyone with lots of great food and conversation. Although it was inside Nicky's provided a picnic-like atmosphere with hamburgers and all the fixings.

September 2016 - Wilf Tiefenbach chaired the open forum in which everyone around the table discussed their summer and any health problems that they might have had.

October 2016 - The Spring meetings for 2017 will be held March 30th and April 27th, 2017 at Nicky's Café, Eighth Avenue and Winnipeg Street. We will decide on the dates and times for the Spring Picnic and fall meetings at future meetings.

Open Forum: David Cotcher did a presentation on the "Citizens Health Information Portal" which is a pilot project for residents to be able to access their own health records online. David gave us examples of the information and how we would be able to use it. David also answered questions from the members. A summary of David's presentation follows.

eHealth Saskatchewan Citizen Health Information Portal Pilot Program

In February 2016 eHealth Saskatchewan started a 6-month pilot program called the Citizen Health Information Portal (CHIP) to allow 1000 participants to access their medical information online. When I heard this announcement in the media, I emailed eHealth to express interest. They sent the registration information and I signed up as a participant.

The CHIP pilot includes online access to:

- Lab Test Results including Blood Tests, Arterial Blood Gas, Stool Sample (FIT) and other test results.

- Vaccination/Immunization History (not including the seasonal Flu Shot)
- Prescription Fill History for the past 24 months
- Hospital Visit History with the date and time of admission. This does not currently include the reason for the hospital visit.
- Medical Procedures information entered by the user to track history.

I did not have any new Lab Tests during the time of the pilot program but I found it interesting to review information back to 2012 from previous tests. I used the Medical Procedures section to enter the history of the dates of my tracheostomy tube changes and my cataract surgery last year.

CHIP has other sections for user entered information:

- Family History
- Medical Conditions
- Allergies
- Measurements including weight, blood pressure, blood sugar, etc.

CHIP has provisions for Scheduling: Appointments, Reminders and Messages. At present this would only work if your Doctor or other medical practitioner are part of the CHIP Pilot which did not apply in my case. There is also provision to share user information with medical personnel.

The CHIP Pilot ran from February to August 2016 and had 1100 participants. Over the course of the program the participants were asked to respond to surveys of their experiences. Overall eHealth received positive response from participants. The CHIP pilot has been extended for another year to August 2017 with current users while the results are evaluated. The future of the Citizen Health Information Portal will depend on eHealth Saskatchewan exploring improvements and opportunities to extend CHIP to all Saskatchewan residents.

References:

- <https://www.ehealthsask.ca/citizen-engagement/CHIP/>
- <https://www.saskatchewan.ca/government/news-and-media/2016/february/16/ehealth>
- <https://www.saskatchewan.ca/government/news-and-media/2016/november/14/digital-health-week>

The follow articles are a collection of articles that Dr. Richard Bruno has submitted to the Facebook group “The Post-Polio Coffee House” which is a forum for Polio Survivors. They are reprinted with Dr. Bruno’s permission.

Posted by Dr. Bruno June 16, 2016

Osteoporosis

There have been a number of Coffee House members asking about treatment for osteoporosis. Here’s one e-mail I received:

Q: I have both osteoporosis and acid reflux. I just read that the anti-reflux drug I’m taking may cause my bones to get thinner. I already am taking Fosamax, which I also read can cause my jawbone to die! Should I stop both these pills?

A. Polio survivors are finding themselves between drugs and a soft place, that soft place being their bones. Osteonecrosis – bone death – was reported in the jaws of 63 patients taking bisphosphonates, drugs that are given to increase bone density. Fifty-seven patients received intravenous bisphosphonates as treatment for cancer. But, six took Fosamax, the well-known oral anti-osteoporosis medication. Dentists across the country have reported about fifty cases of jaw osteonecrosis. Given that about three million women take Fosamax, fifty is a small number of cases. Even if you assume that only about one percent of problems caused by a given medication are reported, jaw osteonecrosis would occur in only two-tenths of one percent of women taking Fosamax. Still, if it’s your jaw that’s dying, who cares about percentages? So, the FDA now wants labels on all bisphosphonates to warn about the possibility of osteonecrosis.

If drugs to treat osteoporosis aren’t causing enough worry, in late 2006 a study of nearly 150,000 people over 50 year-old found that taking proton pump inhibitors (anti-acid reflux drugs like Nexium) for more than a year increased their risk of a hip fracture by 44 percent. The higher the dose and the longer the drugs were taken, the risk of a hip fracture, especially among men, rose nearly 200 percent. The increased risk of fracture may be caused by proton pump inhibitors interfering with your body’s ability

to deposit calcium inside your bones to increase their strength. This unfortunate side effect of proton pump inhibitors is a two-headed dragon for polio survivors.

The first head is that polio survivors with paralysis, both female and male, have osteoporosis more frequently because they either haven't been "pushing" on their bones by standing on their legs (the result of using a weight-bearing brace, crutches or a wheelchair) or because their weak or paralyzed muscles haven't been "pulling" on bones. It's the pushing and pulling that makes calcium bind inside bones so they won't become brittle.

The second dragon's head is that our 1985 Post-Polio Survey found that gut problems, including ulcers and acid reflux, are between six and fifteen times more common in polio survivors than in the general population. To make things worse, sleep apnea, which we have found in 25% of Post-Polio Institute patients, may increase reflux.

Oh, and another "head" has just reared its ugly self. A 2007 study of 5,000 adults 50 year-old and older found that daily use of the newer antidepressant medications (selective serotonin reuptake inhibitors — SSRIs -- like Prozac) decreased bone density by as much as four percent and doubled the chance of breaking a bone. What's more, the higher the dose of an SSRI, the risk of falling increased by fifty percent.

So, what's to be done about your belly, your brain and your bones? All female polio survivors, and males who have muscle weakness or paralysis, should have a DEXA bone density scan to determine if they have osteoporosis or osteopenia, a lesser decrease in bone density that still increases your risk of fracture. If you have decreased bone density, ask your doctor if you could try to increase calcium, vitamin D and protein before starting a bisphosphonate. If you need medication, ask about using calcitonin, a hormone that also increases calcium inside your bones, or the non-bisphosphonate drug Evista.

If you are taking a proton pump inhibitor or an SSRI, ask your doctor if increasing calcium would be helpful in combating these drugs' unwanted effects on bone density and falling. And, Postmenopausal women should talk to their gynecologist about whether hormone replacement is an appropriate treatment.

Unfortunately, fatiguing exercise or walking to "push and pull" on bones is not a treatment for osteoporosis or osteopenia in polio survivors, since exercise can cause muscle weakness and exactly what you're trying to prevent: a fall and a fracture.

Posted by Dr. Bruno June 2, 2016

For The Bones of Women (and Men) Who Had Polio...

Fearing Drugs' Rare Side Effects, Millions Take Their Chances With Osteoporosis

NY Jazz Times

By GINA KOLATA JUNE 1, 2016

Millions of Americans are missing out on a chance to avoid debilitating fractures from weakened bones, researchers say, because they are terrified of exceedingly rare side effects from drugs that can help them.

Reports of the drugs' causing jawbones to rot and thighbones to snap in two have shaken many osteoporosis patients so much that they say they would rather take their chances with the disease. Use of the most commonly prescribed osteoporosis drugs fell by 50 percent from 2008 to 2012, according to a recent paper, and doctors say the trend is continuing.

Last month, three professional groups — the American Society for Bone and Mineral Research, the National Osteoporosis Foundation and the National Bone Health Alliance — put out an urgent call for doctors to be more aggressive in treating patients at high risk, and for patients to be more aware of the need for treatment. It followed a flurry of recent articles in medical journals documenting and bemoaning patients' abandonment of traditional osteoporosis drugs. But osteoporosis experts are afraid their efforts will do little to change minds.

"Ninety percent of patients, when you talk to them about starting one of these drugs, won't go on," said Dr. Paul D. Miller, medical director of the Colorado Center for Bone Research, a medical practice in Lakewood. "Ninety percent who are on the drugs want to come off. The fear factor is huge."

Half of those who start taking the drugs stop within a year. Even patients who just broke a hip, which makes another hip fracture extremely likely, are refusing them. In 2011, only 20 percent of patients discharged from a hospital with a broken hip had a prescription for one of the drugs, compared with 50 percent in 2002.

There is little question that fractures caused by fragile bones are a real problem, particularly for women. A 50-year-old woman has a 50 percent chance of having an osteoporotic fracture in her remaining years. The drugs, meant to be started when bone density falls very low and the chance of a fracture soars, can reduce that risk by half, studies show.

But to many, it matters little that the drugs' frightening side effects are extremely rare. Estimates are that 10 to 40 in 100,000 osteoporosis patients taking the drugs — including alendronate, ibandronate, risedronate and zoledronate — have sustained broken thighbones. Fewer than one in 100,000 have had the jawbone problem.

“You only need to treat 50 people to prevent a fracture, but you need to treat 40,000 to see an atypical fracture,” said Dr. Clifford J. Rosen, a professor of medicine at Tufts University who has no association with the makers of the drugs.

Lawsuits over the rare side effects resulted in large jury awards and drew widespread attention. And after reports of these problems began to surface, the Food and Drug Administration requested that the drugs' labels include a warning about the association.

Doctors had hoped that a new class of medications might avoid the rare side effects, but their hopes were dashed when Amgen announced the same problems in a clinical trial of a drug called romosozumab: a sudden shattering of a thigh bone in one patient and an area of jawbone that inexplicably rotted in two.

“This was the new miracle drug,” Dr. Rosen said. “It means these effects might occur with any of the newer drugs for osteoporosis.”

Some patients say that even though their doctors have explained the relative risks to them, the specter of those side effects frightens them.

That is what happened with Mildred Canipe, 79, who lives in Charlotte, N.C. She had a spine fracture two

years ago and now lives with continual back pain. She worries about another spine fracture or, even worse, a fractured hip. But she resists taking osteoporosis drugs, she said, because she tends to have side effects with almost any drug, and that makes her think that if anyone will suffer an atypical fracture from the medicine, it is she.

“Of course I am worried about my bones,” Mrs. Canipe said. “Who wouldn't be? But I am between a rock and a hard place.”

She is right to worry about a hip fracture, doctors say. Those injuries are often the start of a downward spiral for older adults. Many never walk normally again. Many end up in nursing homes, unable to care for themselves.

“You see someone go from being a mobile elderly person to someone gripping a walker, afraid to move,” said Joan A. McGowan, who directs the division of musculoskeletal diseases at the National Institute of Arthritis and Musculoskeletal and Skin Diseases. “And the less they walk, the more frail they become.” Dr. McGowan has no associations with makers of osteoporosis drugs.

The pain from spine fractures may improve, but physical disfigurement does not. Many patients with osteoporosis have multiple fractures of their spines. They become hunched and have trouble breathing. Their posture makes it hard for their hearts to pump blood, Dr. McGowan said, adding, “It's not pretty.”

Yet it is an uphill battle trying to persuade people to take the drugs, said Dr. Steven T. Harris, an osteoporosis specialist at the University of California, San Francisco.

“I have that discussion all day every day with my patients,” he said.

One issue, Dr. Harris said, is the relentless promotion of diet and exercise for patients with fragile bones, which, he said, is insufficient to protect them from fractures. It gives people a false sense that they can control their risk.

Another, said Dr. Ethel S. Siris, an osteoporosis expert at Columbia, is that with the drugs off patent, there is no longer an aggressive advertising push to make people aware of them. Their cost ranges from less than \$10 a month for alendronate pills to about

\$1,200 for a once-a-year infusion of zoledronate.

Doctors who have seen one of the rare patients who have an atypical fracture are shaken by the experience and have to remind themselves of the power of the data showing that the drugs' benefits far outweigh their risks.

Dr. Elaine Carlson, who until her recent retirement practiced internal medicine in Kennebunk, Me., had a patient who sustained two such fractures. The patient, 89, who asked that her name not be used to protect her privacy, said her left leg had broken suddenly when she was walking across her kitchen floor. A surgeon put in a rod and three screws, and it healed. Then, she said, her right thigh began to hurt six months later.

She called Dr. Carlson's office and was talking to her nurse practitioner when suddenly her right leg broke. She saw three doctors and had two operations before it healed, but she still cannot walk normally and can no longer do the gardening she loves. "I hobble around on a cane," she said. "I am a cripple." She called the drug she took for osteoporosis "that wretched, dreadful stuff."

Having that happen to her patient was "very tough, very tough," Dr. Carlson said. And when the next osteoporosis patient came to her office? "Yeah, you do hesitate," she said. "Your job is 'do no harm.'"

But Dr. Carlson said she had continued to prescribe the drugs. "You do have to stick with the science," she said.



Posted by Dr. Bruno April 30, 2016

How Polio Survivors Can Avoid Tracheostomies

By John R. Bach, MD.

Physical Medicine & Rehabilitation, University Hospital,

University of Medicine & Dentistry of New Jersey, Newark, New Jersey

Dr. Bach is in charge of the Center for Noninvasive Mechanical Ventilation Alternatives and Pulmonary Rehabilitation and has spoken and written extensively. (See "Management of Patients with Neuromuscular Disease" by Hanley & Belfus (2003).

Dr. Bach wrote "Respiratory Muscles Aids to Avert Respiratory Failure and Tracheostomy," which can be found at <http://www.ventusers.org/edu/ConfCall2013Bach.pdf>. His talk supported the premise that "polio survivors can virtually ALWAYS avoid tracheostomies even if continuously (noninvasively) ventilator dependent." However, If you can't speak or swallow, then you do need a tracheostomy.

Dr. Bach describes his patients. My first patients were those who used ventilators since having had polio. Then, I started seeing patients who had used iron lungs but had weaned from them but now need to use noninvasive ventilation. There are also some people who never before needed assisted ventilation until recently.

Dr. Bach on the first decision. First, it should be determined if polio survivors are symptomatic for nocturnal under ventilation. It is also possible that there could be a second condition like lung disease (failure of oxygenation) especially if one was a heavy smoker. Most of the time, though, the symptoms are from muscle weakness (failure of ventilation) for which the treatment is nocturnal ventilation. This is most likely for the survivors of polio. The treatments are very different. For lung issues, the solutions include bronchodilators and oxygen. But, for muscle weakness the treatment is the use of respiratory aids which include noninvasive ventilation and mechanical coughing aids. If a patient has both problems, eg, lung problems due to smoking and

neuromuscular weakness due to polio, a decision may need to be made as to which is the primary problem and treat it.

Dr. Bach on breathing muscles. Inspiratory muscles assist with inhaling. Shortness of breath when lying flat (orthopnea) is a sign of a weak diaphragm (an inspiratory muscle). Many polio people use pillows to support their backs to prevent shortness of breath when they sleep, but the best solution for weak inspiratory muscles is intermittent positive pressure ventilation (air under pressure when inhaling) from a ventilator and via a nose interface. It takes about 20 ml of water pressure to ventilate someone who has severe muscle weakness.

Expiratory muscles (mostly the abdominals) assist with coughing. If survivors get a cold, they may not complain of shortness of breath but of anxiety and difficulty sleeping due to high blood carbon dioxide levels.

It is not helpful to use CPAP and only minimally helpful to use bilevel devices if breathing muscles are weak, because the air blowing in when we exhale is counterproductive.

Bulbar (throat) muscles protect the airways. There isn't anything to be done for bulbar muscle weakness when it results in continuous aspiration of saliva into the lungs but in polio that almost never happens, which is why tracheostomy tubes are unnecessary.

Dr. Bach on weak coughing muscles. Weak coughing muscles keep one from getting rid of the bacteria, etc. in the lungs, which results in pneumonia risk. The first thing an ER physician normally would do is to give oxygen, and if the CO₂ is already high it will "go through the roof." This is why and how many polio survivors get intubated and, after the pneumonia clears up, many are trached. It is not necessary. If a person could speak and swallow at least a little before getting intubated he/she certainly does not need a tracheostomy. Do polio people have trouble swallowing? No. But, people with ALS have trouble swallowing and they can need tracheostomy tubes.

Dr. Bach on CoughAssist (Philips Respironics). Some people who have a trach think that it is easier to suction mucus when they have a cold if they

have a trach. The only people who think this are those who don't know how to use the CoughAssist through the nose and mouth. For that matter, it is also much better than suctioning the airways to use it via a trach tube too. It is best to use the CoughAssist with an abdominal thrust and at least 35 ml of water pressure in and out. A manually assisted cough will get most polio people a functional cough to help them through most problems, so a cough machine is not as necessary for everybody. Dimi Italia s.r.l., Seoil Pacific Group, B & D Electromedical and Siare Engineering International Group S.r.l. also manufacture cough devices.

Dr. Bach on trach tubes. Four out of five people who get a trach will die because of the trach. Problems include mucus plugs, a fistula between the esophagus and trachea (windpipe), and granulations around the trach that bleed when the trach is changed. The tube itself can puncture the windpipe or trachea, or even an artery. People with trach tubes also carry many bad pathogens, so it is not surprising that people with trachs have a greater number of serious infections than those who use noninvasive ventilation. Trach tubes should be removed in those who can speak and swallow food and can co-operate and communicate.

Dr. Bach on CO₂. Too much CO₂ in the blood causes acidity just like CO₂ causes acid rain. Some CO₂ is needed to trigger the brain to tell muscles to breathe. Most labs do not measure end tidal CO₂ but do painful arterial blood gases which make people hyperventilate from the pain. Painless end-tidal CO₂ is actually much more useful.

Dr. Bach on oxygen use. It's a terrible mistake for polio survivors (without lung diseases) to use oxygen. Oxygen use turns off the drive to breathe, and causes the CO₂ levels to rise. Any polio survivor who has respiratory problems, sees a physician, and is sent home with oxygen will be back for treatment of pneumonia or respiratory failure sooner than if they had not been treated at all. The problems that polio survivors have are weak muscles and extra secretions, and there are solutions for both, ie, the treatment is either assisted ventilation and/or assisted coughing.

Dr. Bach on testing. Pulmonary function testing is for lung disease, not muscle weakness. What polio

people need is the measurement of vital capacity, which is the largest breath one can take both while sitting and lying down. The difference between the two should be less than 7%. Other important spirometric tests include measuring air stacking ability. The needed tests are not done in pulmonary function labs and include the measurement of cough flows, both assisted and unassisted. The assisted-cough flow is measured when an Ambu-Bag (manual resuscitator) is used to “air stack,” ie, retain consecutive volumes of air and hold it in the throat to attain the highest volume. Then pressure is put on the belly, if the abdominals are weak, to cause a cough, and the flow is measured. If the flow is more than 270 liters per minute a polio survivor has little chance to get pneumonia during a cold, but if less, any respiratory infection is likely to result in pneumonia.

Sleep studies (polysomnography) were never meant to test for post-polio muscle weakness, but can be useful to rule out other problems, such as obstructive/central sleep apnea which is NOT the principal problem of polio survivors. If a pulmonologist sends someone for a sleep study and they have weak inspiratory muscles, they will treat the patient incorrectly. CPAP is useless for those with breathing muscle weakness, and BiPAP suboptimal particularly at the usual settings used (Inspiratory pressure of 10; Expiratory pressure of 5).

Dr. Bach on oximeters. All polio survivors should have oximeters to assist with the protocol to prevent pneumonia. When sick, use the oximeter to be sure it never registers below 95%. If it does, it means one of two things. One, your CO₂ is high and ventilation is needed. Two, secretions are high and assistance with coughing is needed. If neither treatment is used, the situation worsens and when taken to the ER, oxygen is offered which often results in breathing arrest and emergency intubation, then unnecessary tracheostomy. Remember, if this happens, people can have the tube or trach removed and be successfully managed using noninvasive ventilation. (See Extubation of patients with neuromuscular weakness: a new management paradigm, Bach JR, Gonçalves MR, Hamdani I, Winck JC. Chest. 2010 May;137 (5):1033-9.)

Dr. Bach on ventilators. Ventilator use rests a weak diaphragm and weak inspiratory muscles during sleep, and the result is feeling stronger, better during the day and blood gases are better, ie. CO₂ is more normal. The way to rest the muscles is to use a ventilator using pressures of 18-20 cm of water, not by using CPAP or BiPAP. Remember: It is not possible to turn off the expiratory pressure on a BiPAP machine and the user cannot air stack using it. Air stacking is important to stretch the lungs to full capacity, because if the vital capacity is 50%, that means that half of your lungs are not being used and they “close down.”

Dr. Bach on what breathing device to use. Many polio survivors used negative pressure machines (iron lungs, chest cuirasses, pulmowraps) in the early days, but they caused obstructive apneas and the users experienced desaturations and high blood pressure. I don't recommend negative pressure for anybody any more. I recommend the LTV Series (CareFusion), Trilogy Series (Philips Respironics), and Newport HT50, HT70 (Covidien) here in the United States.

Dr. Bach on nasal masks. There are hundreds of nasal masks on the market, and I recommend that people try several. If someone has trouble with the nasal mask leaking, then try an oral/nasal device such as the Hybrid™ Universal Interface (DeVilbiss Healthcare) or the lip cover Oracle™ 452 (Fisher & Paykel Healthcare), and the oro-nasal Mirage Liberty™ (ResMed Corp).

Dr. Bach on diaphragmatic pacers. A diaphragmatic pacer is completely useless for polio people because to use the device a person needs a good phrenic nerve and a good diaphragm and if they had them they would need no help at all.

www.doctorbach.com



David Cotcher has been an active member of Polio Regina, our treasurer, for a number of years. He has had a tracheostomy for close to 10 years. He just took regular retirement from his job a few years ago.

Comments by David Cotcher:

In the article How Polio Survivors Can Avoid Tracheostomies, Dr. Bach makes good points about the risk of oxygen use in polio survivors causing high CO2 in the blood. This often requires the use of a ventilator. He states that in almost all cases this can be done non-invasively with a nasal mask and not require a tracheostomy. However the general statements he makes about the health conditions of polio survivors are not applicable in all cases. A tracheostomy should be avoided if possible but needs to be considered as a specific situation with the specialist. I have had a tracheostomy for close to 10 years and it has been very successful for me. Where Dr. Bach states “Four out of five people who get a trach will die because of the trach.”, in my experience with correct selection of the type and size of trach tube, and careful ongoing care by myself and by other health professionals these problems can be avoided. Monitoring of CO2 is very important and end tidal CO2 measurement is available. However Dr. Bach’s statement that “Most labs do not measure end tidal CO2 but do painful arterial blood gases which make people hyperventilate from the pain.” has not been my experience. I have had arterial blood gas tests done many times and it is not painful when done by a trained respiratory therapist. Dr. Bach makes many good comments about avoiding tracheostomies but I believe people should not be overly alarmed by his statements about the risks. I am hoping to write an article about my experience with a tracheostomy for the spring PostBox.

Posted by Dr. Richard Bruno December 11, 2015

Autopsy of a Polio Survivor with Muscle Weakness

This isn’t the first autopsy of a polio survivor with PPS. But it does remind us that:

1) Progressive muscle weakness means motor neurons are dying;

2) The original poliovirus attack killed motor neurons not only in the spinal cord area that controlled this man’s the left leg but also caused “silent damage” THROUGHOUT THE SPINAL CORD, silent in that the patient had no muscle weakness in the right leg or his arms after polio but did have arm and leg muscle weakness beginning at age 58;

3) Neuron death caused glial scars in the spinal cord, the same type of scar our MRI studies found in fatigued polio survivors’ brain activating systems;

4) NONE of the markers for ALS was found.

Conserve to preserve. The neurons you save will be your own!

An autopsy case of progressive generalized muscle atrophy over 14 years due to post-polio syndrome. Oki R, et al. Rinsho Shinkeigaku. 2015 Nov.

We report the case of a 72-year-old man who had contracted acute paralytic poliomyelitis in his childhood. Thereafter, he had suffered from paresis involving the left lower limb with no relapse or progression of the disease.

In his 60s he began noticing slowly progressive muscle weakness and atrophy in the upper and lower extremities. At the age of 72, muscle weakness developed rapidly, and he demonstrated shortness of breath on exertion and difficulty swallowing. He died after about 14 years from the onset of muscle weakness symptoms.

Autopsy findings demonstrated MOTOR NEURON LOSS and GLIAL SCARS not only in the motor neurons in the anterior horns, which were result of his old poliomyelitis, BUT ALSO THROUGHOUT THE SPINE. NO Bunina bodies, TDP-43 or ubiquitin inclusions, which are seen in ALS, were found.

The pathological findings in the patient are considered to be related to the development of muscle weakness.



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 March 30, 2017, and Thursday April 27, 2017 at 3:30 p.m. Nicky's has extra parking at the back and it is wheelchair

accessible. Our Spring Picnic will be held at a time and location yet to be determined.

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.

The executive of Polio Regina would like to wish all our members and their families a Merry Christmas and a Healthy and Happy New Year.

MEMBERSHIP APPLICATION POLIO REGINA Inc.

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

Address _____

Postal Code _____ Phone: _____

Annual membership fee: (Jan.- Dec.) *Membership Fees are due January 5, 2017*

\$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.)

Spring Picnic

Our annual spring picnic was held after our May meeting. It was enjoyed by everyone with lots of great food and conversation. Although it was inside, which was a good thing because it was cool and very windy outside, Nicky's provided a picnic-like atmosphere with hamburgers and all the fixings.



The spring meetings for 2017 will be held March 30th and April 27th, 2017 at Nicky's Café, Eighth Avenue and Winnipeg Street. We will decide on the dates and times for the Spring Picnic and fall meetings at future meetings.