May 2015

Polio Regina Incorporated

POLIO POSTBOX

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Have a Great Summer

Message from the President and Vice-President

Hello Everyone,

We are sure all of you are waiting impatiently for warmer weather, as springtime should be warmer. They are predicting snow tomorrow so let's see what happens! Sometimes they get it wrong, (did we hear that right?). Who is 'they' anyhow?

We had a very nice vacation in Kissimmee, Florida again this winter. We stayed for two weeks. Our son, Brad and Janice, joined us on February 18th, and they stayed a few weeks longer than us, so it was a sad day to leave them on March 10th.

IN THIS ISSUE

We noticed quite a few vacationers stayed longer than they originally planned because of the poor winter conditions throughout Canada and the USA. Of course, if one had to work, they had no choice but to go home.

Wilf had to come home, for work, and also for church responsibilities.

While we were in Florida we had many great days of fun and relaxation, great food with new friends and also family. We drove with Brad and Janice to St. Pete's Beach for one day, on the Gulf of Mexico. The weather was perfect to dip your toes into the Gulf! A few days later we traveled to Cocoa Beach on the Atlantic Ocean for another adventurous day. I love to pick beautiful sea shells! Wilf was not too keen on me bringing them home but I just had to.

Plant City, Florida had a very interesting strawberry festival which we also went to with Brad and Janice. They have been going to Florida for about 15 years and usually scout around for new places to eat and all kinds of interesting things to do, besides the usual "Mickey Mouse' stuff! I, for one have had enough of Mickey and his Pals. Wilf would still like to go back for more!

Brad and Wilf took a whole day to attend the Daytona 500! That is not my cup of tea either! Janice and I had a great day shopping without buying hardly a thing. Our dollar wasn't worth that much so that was a very good deterrent for Canadian shoppers this year. As

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Message from the President and Vice-President continued

everyone knows, the Daytona is a very noisy place to be and my ears certainly could not take that kind of noise. I was so grateful to Brad for going in my place!

We put many miles on our van and Brad put many miles on his 12-seater van, as it fit the 8 of us very nicely. The extra part of the gang were: Brad's good biker friend, George and Joanne and my younger brother, Brian and my sister in law, Lynne. Most days, Brad and Janice, George and Joanne, just went on their own on their Harley's to sight see, and we did our thing, but it was fun when we all got together to travel or go for a meal together.

It was wonderful to get away from the worst of the winter months and enjoy the warm sunshine. We came home to pretty nice weather but it sure did not last too long.

We are off to Winnipeg/Garson, Manitoba for a week and will return in time for the Spring get together with our polio friends!

Looking forward to seeing you all at Nicky's Cafe on May 28th!

With love & Blessings to all,

Carole & Wilf Tiefenbach

A father was at the beach with his children when the four-year-old son ran up to him, grabbed his hand, and led him to the shore where a seagull lay dead in the sand.
'Daddy, what happened to him?' the son asked.
'He died and went to Heaven,' the Dad replied.
The boy thought a moment and then said,
'Did God throw him back down?'

A Sunday school teacher asked her children as they were on the way to church service,
'And why is it necessary to be quiet in church?'
One bright little girl replied,
'Because people are sleeping.'

Last Christmas we lost our dear friend Fred Ramsay. Fred and Blenda Ramsay were founding members of Polio Regina. Fred was the editor of the Polio PostBox from its inception until 2007. He was a great wordsmith and a mentor to me as editor. He was the main reason that I became actively involved in Polio Regina. Fred was always smiling and always in a good mood. Blenda, we miss him too.

The following is Fred's obituary.

FREDERIC RAMSAY

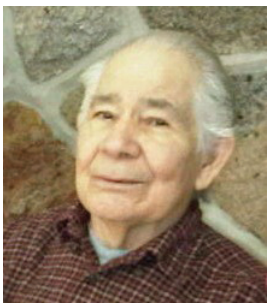
Husband, Father, Grandfather/ Poppa, Journalist, Photographer and Author Fred Ramsay of Regina, passed away peacefully on Tuesday, December 23, 2014. He was born in Ile-a-le-Crosse, Saskatchewan, July 9, 1935. Left to celebrate his life are his loving wife of 57 years, Blenda Ramsay (nee Pearson); his three adoring children, Sheree (Dave) Richardson, Pam Uhl and Rob (Corrie) Ramsay; his six grandchildren, Sharla (Kevin) Blackett, Dustin and Jennifer Richardson, Karly Uhl, Ava and Maisa Ramsay; and his four great-grandchildren, Devstin, Audi-Rae and Kennley-Grace Richardson and Ramsay Blackett. He is also survived by his siblings Charlie Ramsay, Willa (Gary) Vellinga, Alice (late John) Jarbeau and Vicki (late Luddy) Yaremko. He was predeceased by his parents Clara and George Ramsay; and his brother Jim (late Ann) Ramsay. Fred was a passionate writer and photographer. After graduating from the Saskatoon Technical School, he began his career as a reporter for the Saskatoon Star Phoenix, the Moose Jaw Times Herald and the Calgary Herald. After, he worked in Public Relations for the Saskatchewan Wheat Pool for seven years and SaskPower for 27 years. While at SaskPower, he was the editor of Hilines magazine for many years. Fred took hundreds of photos while reporting which enhanced his love for photography. Once retired, Fred focused his time on his growing family but also began a picture Framing Business in his home. He also authored two

books of humorous short stories about his life and accomplishments, "Hit the Road, Fred" and "Hit the Road Again, Fred". Fred was also known as Mr. Fix-it and there was no job too big or too small. His many hobbies included: developing and framing his own photographs, gardening, building butterfly houses, tinkering with Volkswagen beetles and he even carved a totem pole in the backyard. He was a voracious reader and always had at least three books on the go. Fred was a kind and thoughtful man who always put others first. He was a great listener and always knew how to bring a smile to your face. He was an inspiration to all who met him and he will be deeply missed by his family and friends. The family would like to thank Dr. David Warden as well as the staff at Santa Maria for their kindness and dedication to Fred's care. A Celebration of Fred's Life was held at Christ Lutheran Church, 4825 Dewdney Avenue, Regina, on Monday, December 29, 2014 at 1:00 p.m. Friends so wishing may make donations, in memoriam, to Christ Lutheran Church, Santa Maria Senior Citizens' Home, 4215 Regina Avenue, Regina, SK, S4S 0J5 or Polio Regina Inc, 825 McDonald Street, Regina, SK, S4N 2X5.

The following is an article that Blenda Ramsay wrote for the Santa Maria Newsletter. It was published in the May 2012 Polio PostBox.

Profile on Fred Ramsay

By Blenda Ramsay, February 2012



Fred was born at Lle-a-la Crosse, Sask. His father was from Scotland and his mother was Metis with a French Canadian father. The French Canadian priests had built a Catholic Mission there and his father was a boiler engineer for the Mission.

Fred has two brothers and three sisters. His parents separated in mid 40's and the children were placed in Kilburn Hall (an orphanage) in Saskatoon. Fred was about nine years of age at that time. He lived at the orphanage until he was 16. He attended Nutana Elementary School and Saskatoon Technical School. During his youth, he was a newspaper carrier and made extra money by cutting lawns or shovelling snow.

After graduation he got into the Newspaper business and worked as a reporter for the Saskatoon Star Phoenix, the Moose Jaw Times Herald and when we got married in 1957 he was stationed in Red Deer as News Bureau Manager for the Calgary Herald.

We returned back to Sask. in 1959 and he worked in Public Relations for Sask. Wheat Pool (seven years) and then switched to SaskPower where he worked for 27 years.

I know him as a wonderful husband, a father of our three children, grandfather of six grandchildren and great grandfather of three.

He was a writer/photographer and took hundreds of wedding pictures over the years. He was a Toast Master and gave "Toasts" at weddings.

He wrote two books called "Hit The Road Fred" and "Hit The Road Again, Fred" - full of short, humorous stories about his life, work and travels. If you are interested, let me know.

After he retired he started a picture Framing Business in our home.

He had many hobbies and interests. He spent hours doing volunteer work in the community. He was a Mr. Fix-it kind of guy. He carved a Totem Pole on a tree in our back yard - thus the picture of a totem pole on the wall in his room. He loved gardening and tried his hand at making wine from some berry bushes we grew. He owned and drove several Volkswagens.

He was diagnosed with Alzheimer's in spring of 2006. Fred enjoyed attending the Day Program at Pioneer Village for almost a year.

In April, 2011 he became very ill and spent some time in Hospital before moving to Santa Maria Sr. Home.

At The Meetings

December 2014 - Our annual Christmas party was held on December 11th at Nicky's Café. Murray Grant reported that he had purchased the film series "The Roosevelt Story" DVD's from PBS and would let anyone who is interested in viewing it borrow it from him. After the meeting we all enjoyed a turkey dinner with all the trimmings and were able to visit with fellow members after the meal.

March 2015 – This was our annual general meeting. Treasurer David Cotcher presented the annual financial statement for 2014 with comparative figures for 2013. We held elections for our executive.

The following are the Executive Officers of Polio Regina Inc. for 2014-2015:

President – Wilf Tiefenbach

Vice-President – Carole Tiefenbach

Secretary – Ivan Jorgensen

Treasurer – David Cotcher

Phone Co-ordinator – Carole Tiefenbach / Blenda Ramsay

Archivist/Librarian/Web Master – Peter Huang

Post Box Editor – Ivan Jorgensen

Director – Blenda Ramsay

Dr. Mavis Matheson who has served on the executive for many years announced that she and Adam will be moving to BC in June.

Open Forum: Wilf Tiefenbach led the open forum. This was a general discussion with everyone having a chance to tell us about their experiences in the last year.

April 2015 – We decided that the next Polio Regina meeting will be at our Spring Picnic which will take place on Thursday, May 28th at 5:00 p.m. at Nicky's Café and that the fall meetings will be Thursday, September 24th and Thursday, October 29th, both at 3:30 p.m. at Nicky's Café.

Open Forum: The open forum was chaired by Zenny Burton who introduced our guest speaker Allura Weber who is an exercise specialist at the Regina Community Clinic. She gave a presentation on exercises that Post-Polio people would be able to do. She also demonstrated how to do the exercises and answered questions. She also gave us hand-outs with instructions for us to be able to do the exercises at home. This was a very useful presentation because it was tailored specifically to the needs of our group. Some of her presentation and exercises are printed in this issue.

Exercising with Post-Polio Syndrome

Allura Weber, B.Kin, CEP, Exercise Specialist

Researchers have found that those with PPS who engage in regular exercise report a higher level of function and fewer symptoms than those who are not physically active.

Exercise Guidelines

- All exercises should be guided by the individuals fitness level and level of fatigue
- Exercise should not cause muscle soreness or pain
- **Exercise should not lead to fatigue that prevents participation in other daily activities**
- Slow progression of exercises, especially in the muscles that haven't been exercised for a period of time or have chronic weakness due to initial Polio Virus
- Primary focus should be building muscle endurance not muscle strength
- Include strength, aerobic and balancing exercises as well as stretching in your program

Exercise Considerations

- If fatigue is significant, lifestyle changes to conserve energy may be a priority before beginning an exercise program.
- If weakness is significant, strengthening exercises may not be recommended because they can further damage the affected muscles.

- Stretching and aerobic exercise should be considered whenever possible.

Exercise and Post-Polio Syndrome
Author: Beth Grill, PT, DPT, NCS

Muscle Strength vs. Muscle Endurance

- **Muscle Strength** is the amount of force a muscle or muscle group can put out or the amount of weight you can control.
- **Muscle Endurance** is the ability of a muscle or group of muscles to sustain repeated contractions against a certain resistance for an extended period of time.

Strength Training

- **2-3 times / week with a rest day in between**
- **Low resistance or just body weight, high reps**
- **Take rest breaks as needed**
- Strength training may be performed in muscles with polio weakness, however increases in strength may be slower or limited compared to unaffected muscles.

Aerobic Exercise

- **10 – 20 minutes with rest breaks as needed**
- **2-3 times / week with a day off in between**
- It is stated in many research papers that the best aerobic exercise for those with Post-Polio Syndrome is swimming because it is has minimal stress on the tendons and joints. However it is not the best for all polio survivors.
- Any aerobic exercise that causes pain and excessive fatigue should be discontinued.

Balancing

- **Hold positions up to 30 seconds and repeat on both sides**
- Balancing exercises help to prevent falls and help to improve your ability to control and maintain your body's position.
- Make sure to have something sturdy to hold onto if needed.

Stretching

- "Muscle stretching and joint range of motion exercises are important whenever there is muscle weakness. Preventing tightness, where muscle are weak, is important to maximize function and it is particularly important in the chest wall and abdominal musculature if there is a limitation of breathing capacity. Preventing tightness in the hip and knee is important to maximize walking ability when there is significant weakness of the hip and thigh musculature." – Excerpt from the *Handbook on the Late Effects of Poliomyelitis and Survivors*
- It is recommended that programs should be designed and supervised by Physiotherapists and/or other health care professionals.
- These programs are usually tailored to each individual and is supervised for 2-4 months. Programs are adjusted by pain/fatigue levels in those months.
- The program I have created for you is a general program and not tailored to each of your specific needs. Please follow the instructions provided on the program as approved by your Physician or Physiotherapist.

Physiotherapists

- If you wish to consult a Physiotherapist for an individualized program, RQHR will provide up to 4 free services within a 6 month period.
- Exercising is important in our day to day lives, but before you start an exercise program please consult your physician.
- If any form of PA or Exercise bothers you please stop doing that activity and consult your physician.

A mother was preparing pancakes for her sons, Kevin 5, and Ryan 3.
The boys began to argue over who would get the first pancake.
Their mother saw the opportunity for a moral lesson.
'If Jesus were sitting here, He would say,
'Let my brother have the first pancake, I can wait.'
Kevin turned to his younger brother and said,
'Ryan, you be Jesus!'

10 Strengthening Exercises You Can Do at Home

Those with Post Polio Syndrome are more susceptible to muscle weakness and fatigue, and have a longer recovery time. However it is still important to work on increasing muscle endurance, balance, and aerobic activities. Do 10-20 minutes of aerobic exercise (i.e. walking, biking, and swimming) with rest breaks as needed, 3 times per week, with a day off in between.

The following exercises provide a variety of balance, and strengthening exercises you can do at home 2-3 days per week. It is essential that you do not work until fatigue and that you take a day off in between. Begin by going through as much of this program as you can. Slowly start adding in more exercises and reps as you are ready.

Disclaimer: Please see you Doctor before starting this program to see if it is properly suited to you. Please do not attempt any exercises you are not comfortable with.

1. Single Leg Balance

Stand behind a chair.
Balance on one leg for up 30 seconds or as long as you can. Use back of chair for support.
Repeat on both legs.

2. Bicep Curls

Sit in a chair. Slowly curl your arms to your shoulders. This can be done using body weight or household objects such as soup cans.
Repeat up to 10 times.

3. Shoulder Press

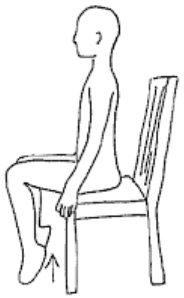
Sit in a chair. Start with hands at shoulder height and slowly press your arms above your head. This can be done using body weight or household objects such as soup cans.
Repeat up to 10 times.

4. Squats

Stand in front of a chair. Slowly lower buttocks to chair. Make sure that your knees never come past your toes.
Repeat up to 10 times.

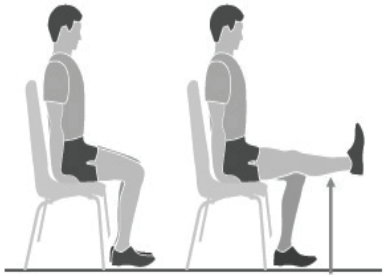
Regina Community Clinic

5. Heel Raises



Sit in a chair. Slowly raise your heels until you are on your tippy toes. Slowly lower back down.
Repeat up to 10 times.

6. Leg Extension



Sit in a chair. Slowly extend one leg upwards until it is straight. Repeat on both legs.
Repeat up to 10 times per leg.

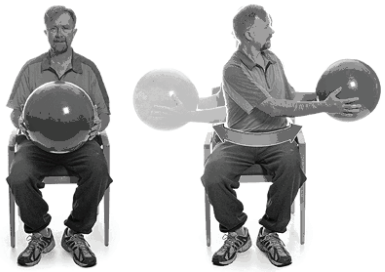
7. Hip Adduction

Sit in a chair with a ball, towel or pillow between your knees. Slowly squeeze the ball between your knees and hold for 3-5 seconds.
Repeat up to 10 times.

8. Seated Marching

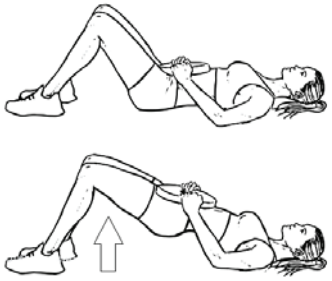
Sit in a chair. Keep your back straight and pull you belly button into your spine. Slowly lift one leg at a time in a marching manner.
Repeat up to 10 times per leg.

9. Seated Rotation



Sit in a chair with a ball, or a pillow in your hands. Keep your back straight and pull belly button into spine. Slowly rotate from side to side.
Repeat up to 10 times per side.

10. Glute Bridge



Lay on your back with knees bent and feet flat on the floor. Slowly lift buttocks off the floor and hold for 2-5 seconds. Slowly lower down to start position.
Repeat up to 10 times.

Before starting an exercise program, please consult your Physician.
If any of the above exercises bother you or cause pain, please stop doing that exercise and see your Physician.

The follow articles are a collection of articles that Dr. Richard Bruno has submitted to the Facebook page "Harvest Center's Post-Polio Coffee House" which is a forum for Polio Survivors. They are reprinted with Dr. Bruno's permission.

Stem Cell Therapy Not For Polio Survivors

Dr. Richard L. Bruno
Chairperson, International Post-Polio Task Force
and
Director, International Centre for Polio Education
http://www.PostPolioInfo.com/

Stem cells are remarkable, embryonic "baby cells" that will grow up to be any kind of cell that the body makes. With all the excitement about stem cells curing spinal cord injury, many polio survivors are asking if stem cells could cure PPS, or even reverse the damage caused by polio itself.

The hope with SCI is that stem cells, injected into the spinal cord, would "bridge the gap" in cut spinal cord axons, which are like long telephone wires that connect brain motor neurons to spinal cord motor neurons and allow the brain to "tell" muscles to move again. This notion requires intact motor neurons below the cut in the cord. And here lies the problem with stem cells "curing" polio or PPS. Even in "mild" cases, the poliovirus killed off least 50% of neurons throughout the spinal cord. Stem cells injected into a polio survivor's spinal cord would not have to just bridge a gap, but have to become new, functioning motor neurons.

What's more, those new neurons would have to send out their own axons to find and activate the specific muscles that were paralyzed when the original axons disappeared 50+ years ago after poliovirus-infected neurons died, by burrowing inches, or in the case of the leg three feet, through the tissues inside the arms and legs.

Finally, the brain's motor neurons would have to send out new axons as well, since the brain's neurons and axons also died. These axons would have to burrow through the entire brain, the brain stem and down through spinal cord to get to the newly-implanted motor neurons, indeed a tremendous tunneling task!

So, the idea of rebuilding a polio-damaged spinal cord would require a "hat trick" of creating new brain and spinal motor neurons, new axons tunneling from the brain to the spinal cord and from the spinal cord to the muscles. Reconnecting a lesioned spinal cord would "only" require the physiological "goal" of bridging the gap between cut axons.

Yes, a possible use for stem cells would be to inject them into the brain, as is done in Parkinson's disease (PD) patients, where they could produce the main brain activating neurochemical, dopamine, which is decreased in polio survivors and causes post-polio fatigue. But, such injections are not widely accepted even in PD patients yet.

So, if stem cells aren't the answer, is there anything polio survivors can do to help their remaining poliovirus-damaged neurons? Recently, there has been research on "neuroprotective" drugs, medications that protect neurons' innards from overuse-abuse that causes post-polio symptoms. Several studies have focused on degenerative diseases, such as Parkinson's and Huntington's diseases, which involve damaged dopamine neurons. Minocycline, a common antibiotic used to kill a variety of bacteria, and creatine, which helps, to provide energy to muscle cells, have been given to PD patients, who showed a less rapid a decline in function compared to those taking a placebo. However, a study comparing creatine and placebo in 60 PD patients found that, while their mood improved and their need for medication decreased, their symptoms did not lessen.

Vitamin E has been found in eight studies to have some neuroprotective effect in PD, while vitamin C and beta carotene were not helpful. Some research even links coffee's ability to limit blood vessels from opening to protecting neurons against PD, with one cup a day cutting the risk of developing PD by as much as fifty percent. Another dietary supplement, coenzyme Q-10, is being testing to see if it protects PD patients' neurons.

Huntington's Disease patients have also benefited from potential neuroprotectives. Huntington's patients given minocycline had slower progression or

no decrease in physical ability, thinking and memory. Creatine had similar beneficial results in HD.

Should polio survivors take minocycline, creatine and Vitamin E, or order a Starbucks' grande, three-shot cappuccino to prevent post-polio brain fatigue? Not yet. There aren't enough studies to prove that any of these is truly neuroprotective in Parkinson's or Huntington's disease, let alone helpful for polio survivors, in which these substances haven't been studied at all.

Double-blind, placebo-controlled studies of potential neuroprotectives are warranted in polio survivors. For now, the only neuroprotective that we know works in polio survivors is "The Golden Rule:" If anything causes fatigue, weakness or pain, DON'T DO IT! (Or do less of it.)

Restless Legs Syndrome

Dr. Richard Bruno Jan 5, 2015

The authors studied one of two different conditions that are always confused by doctors: restless legs syndrome vs. periodic leg movements in sleep. RLS is a need to move the extremities because of discomfort or disagreeable sensations to relieve the discomfort. PLMS is where your legs and other muscles twitch and jump on their own, which our study found in 50% of polio survivors.

http://www.postpolioinfo.com/library/grm.pdf

We don't know the criteria for the diagnosis of PPS in this study. But, the findings about RLS show the importance for all polio survivors of having a sleep study to diagnose MORE than just breathing problems!

Restless Legs Syndrome and Post-Polio Syndrome

A. Romigieta, et al.
European Journal of Neurology 2014, 0: 1–7

Background and purpose: The aim was to investigate the prevalence of restless legs syndrome (RLS), fatigue and daytime sleepiness in patients affected by post-polio syndrome (PPS) and RLS impact on patient health-related quality of life compared with healthy subjects.

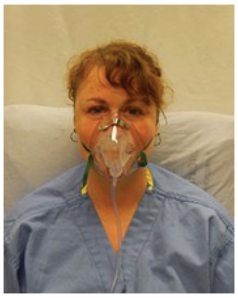
Methods: PPS patients were evaluated by means of the Stanford Sleepiness Scale and the Fatigue Severity Scale (FSS). The Short Form Health Survey (SF-36) questionnaire was used to assess health-related quality of life in polio survivors. RLS was diagnosed when standard criteria were met. Age and sex matched healthy controls were recruited amongst spouses or friends of PPS subjects.

Results: 66 PPS patients and 80 healthy controls were enrolled in the study. A significantly higher prevalence of RLS was found in PPS patients (63.6%) than in healthy controls (7.5%). The fatigue score was higher in PPS+RLS than in polio survivors without RLS. Significantly worse physical functioning, physical ability and bodily pain were found in polio survivors with RLS than in those without RLS. Polio survivors with RLS showed a significant relationship between high scores on the International Restless Legs Scale and more fatigue plus less physical ability, general health, vitality, social functioning and mental health.

Conclusion: Our findings demonstrate a high prevalence of RLS in polio survivors with PPS, and that RLS may negatively influence the health-related quality of life and increase fatigue in PPS patients.

Oxygen: Too Much of a Good Thing

Richard Bruno



"We will give you a little bit of oxygen." "No we will not!"

Exactly right. Oxygen is like Tylenol in the hospital or in an ambulance. Don't feel well? They "give you a little bit of oxygen."

As with any other drug, there needs to be a REASON for the prescription of oxygen (O_2), because O_2 DEPRESSES polio survivors' damaged breathing control center in the brain stem. Also, a weak diaphragm causes some polio survivors to retain carbon dioxide (CO_2) which is toxic. If there are

medical or surgical issues that cause MEASURED blood oxygen to drop to the low 90s, then both giving O_2 and TREATING the cause could be life saving.

But, without a respiratory or other disease causing O_2 to be in the low -- for example for coming out of surgery or using CPAP or Bi-Pap -- polio survivors should not just be given "little bit of oxygen" for no reason. If you just have apnea or shallow breathing during sleep, CPAP or Bi-Pap should bring your O_2 into the normal range without need for extra O_2.

CO_2: The Gas Polio Survivors Have Trouble Getting Rid Of

Polio survivors retaining carbon dioxide is not discussed enough. I got a call from an anesthesiologist in North Carolina about a polio survivor who'd had her gall bladder removed and in the recovery room was "fighting the tube" placed in her windpipe during the surgery. Well, nearly every post-op patient "fights the tube." But, the nurses thought she was having trouble breathing, even though her measured O_2 was 96%, so they turned up the O_2. Turns out the patient's trouble was retaining CO_2; the extra O_2 depressed her breathing, she went into respiratory arrest and died. The anesthesiologist almost cried when I explained this to him.

"Why don't we know about this!?" he asked.

I thought, "If only North Carolina had the Internet where a doctor could search 'surgery, breathing, polio survivors' and find the Post-Polio Library and 'Preventing complications in polio survivors undergoing surgery'." http://postpolioinfo.com/lib_surgical.php

Yes, yet again, polio survivors have to read and know more than their lazy and ignorant physicians, to just say "no" to anything that could cause harm and always discuss with the anesthesiologist before any test (e.g., a colonoscopy) or surgery using anesthesia that polio survivors can retain CO_2 and the dangers of O_2 suppressing breathing.

Finding, No Surprise

Richard Bruno

I know this finding is no surprise. Viruses mutate. Remember that it was recently discovered that type one polio virus mutated in the Congo causing a 40% death rate and paralysis and young adults instead of infants.

So the D68 virus mutating is no shocker nor is it something to be terrified of. D68 is not "THE NEW POLIO!" There were 107 cases of weakness or paralysis compared to thousands of children with just the respiratory illness for hospitalized and what the CDC estimates are millions of children who were infected and basically got just a cold. These numbers are a lot better than those for the polio epidemic's. Anti-bodies were drawn before and after the huge 1948 North Carolina polio epidemic in that epidemic 70% of children were infected with the poliovirus, about 5% developed "non-paralytic polio" and 1 to 2% were paralyzed. If you apply those numbers to the D68 outbreak, there should have been at least 10,000 cases of paralysis or weakness last year, not 107. Link found between children with paralysis and 'more polio-like' strain of enterovirus D68, study says By Ariana Eunjung Cha March 30 at 6:31 PM THE WASHINGTON POST Genetic sequencing of a virus found in respiratory secretions of children in California and Colorado who suffered from paralysis or muscle weakness last fall reveals that they were infected with a mutated strain of enterovirus D68 that is closer to polio than other strains common in previous years. The study, published Monday in Lancet Infectious Diseases, sheds new light on one of the most troubling medical mysteries of recent years. Amid a nationwide outbreak of severe respiratory illness, doctors at hospitals nationwide began to report that they were seeing an alarming number of children with unexplained weakness in an arm or a leg to complete paralysis that required them to be put on ventilators. Treating physicians noted that many of the children appeared to be infected with enterovirus D68, but researchers were cautious about drawing a causal link because virus had been bouncing around the world since the 1960s and had typically only caused breathing issues such as coughing and wheezing.

While the research does not provide a definitive link -- that would only be established if the virus were found in the spinal fluid and it was not -- it provides the strongest evidence to date of the link between enterovirus D68

and paralysis. The researchers theorize that the reason the virus was not found in the spinal fluid could be because the samples were taken too late. Scientists also tested the children for the presence of other pathogens capable of causing the symptoms but didn't find other viruses, bacteria, fungi or parasites.

The new research reveals that the children had a novel strain of the virus, called B1, which emerged about four years ago. That strain has only five to six coding differences from previous strains that were commonly found in the United States but each of those are mutated in the direction of polio or another nerve-damaging virus known as EV-D70.

"These are changes that may have made the virus more polio-like," said Charles Chiu, an associate professor at the University of California-San Francisco who worked on the study.

While the study identified D68 as a possible trigger of the paralysis, it was not able to shed any light on another key question: Why have some children been affected so severely while others have been fine?

The study included a pair of siblings with a 100 percent genetically identical strain of the virus. One experienced muscle weakness and paralysis while the other only experienced upper respiratory symptoms.

Chiu said the study suggests that there are individual differences in patients' biology that may determine how the virus affects them. A group of researchers at Johns Hopkins and at Children's Hospital Colorado is gathering DNA from patients around the country to try to explain the different outcomes.

Kevin Messacar, an infectious diseases specialist at Children's Hospital Colorado, where the first large cluster was identified, said the hospital has established a new clinic to treat and study the children who have been affected. He said the researchers will be looking at genetic and immune response in children that may make them more susceptible to paralysis

"If you think about viruses like polio back in the day hundreds of people were infected whereas only a handful would end up with paralysis. Other illnesses like influenza--many will get fever and achy joints and some will get severe respiratory disease. So I think everybody reacts to infectious diseases differently and it's not unusual to see different diseases in different people," Messacar explained.

The question is critically important as the vast majority of children affected have not fully recovered. Last fall, many doctors had said they were hopeful the muscle weakness and paralysis were temporary but that has not turned out to be the case. In the Lancet study, none of the children had fully recovered by day 30. Chiu said that the researchers now have 60 day data and 70 percent of the children had minimal to no improvement.

"This is starting to look more like polio unfortunately where the paralysis appears to be permanent or semi-permanent. This is why there is such an urgency for more research to investigate this," Chiu said.

The Lancet study's authors -- which included researchers at hospital centers in Aurora, Colo., San Francisco, Palo Alto, and Los Angeles -- emphasized the need for ongoing surveillance for D68 and the need for more resources to develop an effective treatment or vaccine.

With the start of enterovirus season starting in a few months -- it tends to peak in late summer and early fall -- researchers say they cannot predict whether the B1 strain of enterovirus D68 will make a come back. At any given time there are typically more than 100 different enteroviruses and rhinoviruses floating around that cause the common cold and in any given year doctors may only see a few of those strains circulating.

"Even if we don't see it again this year, which would be the best case scenario, it doesn't mean we should stop doing research. The fact is if you have a virus associated with the common cold that is linked to paralysis it is concerning," Chiu said.

Intravenous Immunoglobulin (IVIG) Does Not Treat PPS

Richard Bruno

I've been writing since 2004 about the failure of intravenous immunoglobulin (IVIG) as a treatment for PPS in spite of glowing "press releases" from the IVIG manufacturers (please see below).

Independent researchers have reviewed the published studies on IVIG in 508 polio survivors and have come to the same conclusion: There is no evidence that IVIG helps with any PPS symptoms.

INTRAVENOUS IMMUNOGLOBULIN FOR POSTPOLIO SYNDROME: A SYSTEMATIC REVIEW AND META-ANALYSIS.

Yao-Hsien Huang, et al. BMC Neurology 2015, Number: 39 March 22, 2015

SUMMARY

Background: Post-polio syndrome (PPS) is characterized by progressive disabilities that develop decades after prior paralytic poliomyelitis. Because chronic inflammation has been suggested as causing the development of PPS, immunomodulatory management, such as intravenous immunoglobulin (IVIg) administration, may be beneficial.

Methods: We performed a systematic review and combined analysis of 3 published randomized, placebo-controlled trials of 241 patients and 5 prospective studies of 267 patients that evaluated the effect of IVIg in managing PPS. Pain severity, fatigue, muscle strength, physical performance and, quality of life were measured before and after IVIg infusion.

Conclusion: The present review indicated that IVIg is unlikely to produce significant improvements in pain, fatigue, or muscle strength. Thus, routinely administering IVIg to patients with PPS is not recommended.

INTRAVENOUS IMMUNOGLOBULIN (IVIG) DOES NOT TREAT PPS.

Dr. Richard L. Bruno

Chairperson, International Post-Polio Task Force and Director, The Post-Polio Institute and International Centre for Polio Education
PostPolioInfo.com

Let me tell you an unbelievable story, and I mean literally unbelievable.

Sweden, 2004 – "Xepol" was described in Karolinska Institut press release headlined "Promising anti-inflammatory treatment for post-polio syndrome." Sixteen polio survivors with muscle weakness were treated with Xepol, which is intravenous immunoglobulin (IVIG), a standard treatment for inflammatory diseases. "Most patients reported improvements in their physical status. However, the value of this is unclear, since this first study did not include a placebo group." Value unclear without a placebo group? No kidding.

Sweden, 2006- A Xepol study was finally published in a medical journal. IVIG was given to 73 polio survivors and placebo to 69, then given again in three months. There was no improvement in fatigue, general muscle strength, pain, walking speed, balance or sleep quality. There were only four benefits: A "selected study muscle" increased in strength by 2%, a greater decrease in "significant pain," a 10% increase in reported "vitality" and a 19% increase in physical activity compared to the placebo group.

Did Xepol help polio survivors? First, the placebo group had worse symptoms than the Xepol group to begin with, making it harder for them to show any benefit. Second, this was not a placebo-controlled study. IVIG subjects had noticeable and unpleasant side-effects as compared to the placebo group: 30% reported itching and rash with IV, 29% reported headache, 19% reported nausea and 10% reported feeling cold. Since as many as 30% of the Xepol subjects could have figured out that they were getting IVIG, any improvements could be due to the placebo effect.

Sweden, 2008 - A press release trumpeted, "PHARMALINK REPORTS POSITIVE RESULTS FOR XEPOL," "effective and well tolerated" in the same subjects reported in the 2006 journal article, but who were now one year post treatment. Pain, walking ability and self-report of health "all showed significant and clinically meaningful results," the release hailed. Said Pharmalink's managing director, "We are very excited about this data as patients in the treated group have experienced a reduction in disease symptoms after just 12 months."

Whoa! First, the published six-month study showed no significant improvement in pain or walking ability. Second, since the new twelve-month data hasn't been published, so we can't know if any of the new results produce a "significant and clinically meaningful reduction in disease symptoms." Third, even the release said that the placebo group also reported a decrease in pain and improved walking after 12 months.

Finally, the company was "very excited" because polio survivors had a reduction in symptoms "just 12 months" after taking Xepol?" "Just 12 months?" Can you imagine any drug company excitedly proclaiming, "NEW HEADACHE MEDICATION WORKS JUST 12 MONTHS AFTER TAKING THE PILL?"

North America, 2009 – I received e-mails from polio survivors in the US and Mexico. Doctors were making presentations about Xepol to post-polio support groups and then asking polio survivors for donations to perform studies using Xepol.

Sweden, 2010 – "Pharmalink AB, today announced agreement with Grifols for the acquisition of Xepol (R)…human immunoglobulin for the treatment of (PPS). This agreement marks a significant milestone in Pharmalink's corporate development. Grifols will develop the PPS product opportunity. In several clinical trials lead by a team of physicians at Karolinska Institutet, immunoglobulin has shown significant and clinically meaningful results in pain, walking ability and quality of life by down-regulating the inflammatory process in the nervous system of PPS patients."

"Significant and clinically meaningful results in pain, walking ability and quality of life?" Not in the one published study. And, none of the studies, published or not, ever measured "down-regulating the inflammatory process."

What is "significant" is the "milestone in Pharmalink's corporate development," having sold Xepol to a company with the cash to "develop the PPS product opportunity" without polio survivors having to fund it.

I've been around long enough to remember an 1995 NIH study that found that high doses of prednisone, the king of anti-inflammatory drugs, didn't decrease PPS symptoms but did cause horrible side effects. A 2007 Norwegian study found no change in polio survivors' "fatigue and muscle strength" three months after IVIG treatment."

One post-polio boat sailed long ago: Inflammation does not cause PPS. That is unless you're a corporation that "publishes" research via "very excited" press releases and happens to have a "product opportunity" that may make you a buck… or 1,500 bucks, the cost of just one Xepol treatment.

Fainting and Fatigue in Polio Survivors

By Dr. Richard L. Bruno

Q. I had polio with weakness in my left leg. I recovered and carried on a normal life until the early 1990's when I started to have fatigue, heart palpitations, skipped beats and low blood pressure, especially after I eat. Should my doctor be considering any tie-in with polio?

A. Oh, yes! Fifty years ago polio pioneer David Bodian discovered that every polio survivor had some poliovirus-damaged neurons in the brain stem, the so-called "bulb" of the brain. When brain stem damage was severe "bulbar" polio was diagnosed whose icon, the iron lung, was needed when brain stem breathing-control neurons stopped working. But the most common symptom of "bulbar" polio was trouble swallowing, not trouble breathing. And some "bulbar" polio patients had severe difficulty controlling their blood pressure and heart rate which was the leading cause of death in these patients, not being unable to breathe.

The brain stem neurons damaged by the poliovirus that are responsible for controlling breathing, swallowing and and blood pressure work by way of the vagus nerve, which carries commands from the brain stem to activate muscles in your throat, esophagus, stomach and intestines and also slows your heart rate. But the vagus nerve is a two-way street, since it also "listens" to activity in the gut and sends that information back up to brain stem neurons.

Vagus/brain stem damage disrupting the normal functioning of the gut may explain our Post-Polio Survey findings that swallowing difficulty, diarrhea, colitis, ulcers and constipation are as much as six times more common in polio survivors than in non-polio survivors. And the symptoms you describe may result from poliovirus-damage to the vagus nerve as well as brain stem blood pressure and heart rate control neurons. We have a growing number of post-polio patients who feel exhausted after a meal. We found that, when their stomachs fill with food, the vagus is apparently over stimulated and triggers a drop in blood pressure and heart rate, causing feelings of fatigue and sometimes palpitations. Polio survivors have also been reporting another problem: Food sticking in the upper esophagus. We think this is due to the vagus not stimulating esophagus muscles to move the food downward. When food gets stuck, irritation triggers a painful esophagus muscle spasm that also stimulates the vagus nerve, causing blood pressure to drop and the heart to race or to slow.

Although blood pressure drops our post-polio patients rarely faint, which is consistent with our 1995 Post-Polio Survey finding that polio survivors do not faint any more frequently than those who didn't have polio. But

the 1995 Survey did find that anyone who had fainted even once in their lifetimes reported significantly more daily fatigue than those who had never fainted. This suggests that damage to brain stem blood pressure control and vagus nerve neurons may be coupled to poliovirus damage to bulbar "brain activating system" neurons, those which our laboratory research suggests are responsible for post-polio brain fatigue.

The relationship between fatigue, brain stem damage and low blood pressure links polio survivors to another bunch of very tired folk: those with chronic fatigue syndrome. About one quarter of CFS patients have fatigue that is associated with low blood pressure or increased heart rate. Some CFS patients report fatigue when a hot shower or hot room causes blood pressure to drop, as do about one third of polio survivors. Other CFS patients have blue feet, just like our patients' "polio feet," suggesting that blood pooling in the legs contributes to low blood pressure.

Polio survivors should have a doctor take their blood pressure and heart rate lying, sitting and--if possible--standing. Polio survivors who have fatigue associated with a drop in blood pressure or a slowed or racing heart, need to see a cardiologist who treats low blood pressure. Compression stockings, which push blood back toward the heart, and medications that increase the fluid in your blood or stop blood from pooling in the legs can be helpful. If fatigue follows eating, frequent, small, higher protein meals can prevent the stomach from getting too full and stimulating the vagus nerve. Polio survivors having trouble swallowing should see an ENT doctor. Eating smaller bites of softer foods and washing down each bite can prevent food from sticking in the esophagus. For those who still have a sticking problem, a low dose of the muscle relaxant Klonopin taken 30 minutes before eating can prevent muscle spasms and help food slide down.

Blood Sugar Can Be Too Low in Post-Polio Diabetics

Richard Bruno

In 2000, we measured polio survivors' blood sugar and gave them the same tests of attention and memory that we'd been using to study polio survivors with fatigue. We found that the lower polio survivors' blood sugar the worse they did on the most difficult attention tests. Attention was about 20% BELOW normal for those whose blood sugars were around 80, which is the bottom of the normal range for blood sugar. In fact, polio survivors' ability to pay attention with a blood sugar of 80 was actually WORSE THAN IN DIABETICS with a blood sugar of 65! In terms of focusing attention polio survivors' brains act as if they are hypoglycemic, with blood sugar levels in their brains about 15 points LOWER than the measurement from their doctors' lab.

Today's NY TIMES article shows the danger of one-size-fits-all treating of older diabetics that can cause hypoglycemia, brain brownouts, accidents and even death. How much more should this warning apply to diabetic polio survivors whose brain may already be hypoglycemic! Talk to your doctor about allowing your sugars to run higher.

When Diabetes Treatment Goes Too Far
By KASIA LIPSKA JAN. 12, 2015 NY TIMES

ONE of my elderly patients has Type 2 diabetes and heart disease. He takes a number of medications, including insulin to control his blood sugar levels. A few years ago, he was driving when his blood sugar suddenly dropped. He felt lightheaded for a moment, and then ran into a tree. There are roughly 11 million Americans over age 65 with diabetes. Most of them take medications to reduce their blood sugar levels. The majority reach an average blood sugar target, or "hemoglobin A1C," of less than 7 percent (http://www.mayoclinic.org/tests-procedures/a1c-test/basics/definition/prc-20012585). Why? Early studies showed that this can reduce the risk of diabetes complications, including eye, kidney and nerve problems. As a result, for more than a decade, medical societies, pharmaceutical companies and diabetes groups have campaigned with a simple, concrete message — to get below seven. Many patients carry report cards with their scores to clinic appointments. Doctors are often rewarded based on how many of their patients hit the target.

All of this sounds great. But, at least for older people, there are serious problems with the below-seven paradigm. To begin with, the health benefits of this strategy are uncertain for older people. Those early studies that were the rationale for going below seven were conducted in people with Type 1 diabetes or with younger patients with newly diagnosed Type 2 diabetes. Subsequent trials of older patients raised doubts about the benefits.

Worse, targeting low blood sugar levels can cause harm. In one instance, investigators actually had to stop a trial

early because patients who were targeting hemoglobin A1C levels of six or below had significantly higher rates of death than patients targeting levels in the sevens. We don't know exactly why this happened. What we do know is that aiming for levels below seven increases the risk for "hypoglycemia," or low blood sugar reactions. Severe reactions can result in confusion, coma, falls, fractures, abnormal heart rhythms and even death.

Older people are especially susceptible to severe hypoglycemia. With age, kidneys become less efficient, which causes insulin (or other drugs) to accumulate in the body; this, in turn, can lead to hypoglycemia. What's more, older people often take multiple medications, some of which may interact with diabetes drugs. This, too, may cause hypoglycemia. Using multiple medications or complex insulin regimens also increases the chances of errors, such as taking the wrong dose or the wrong type of insulin. Finally, older people have fewer warning symptoms when they experience mild dips in blood sugar, and this leaves less time for them to react and treat the problem before it becomes severe. This is precisely what happened to my patient.

Given the questionable benefits and the very real risks of going below seven, the American Geriatrics Society and the Veterans Affairs diabetes guidelines have, for years, recommended a cautious, case-by-case approach for older patients. For those with serious health problems, or prior history of hypoglycemia, going below seven may not be worth the risks involved. The problem is that we haven't put these guidelines into practice.

In a new study published today in JAMA Internal Medicine, my colleagues and I used nationally representative data from 2001 to 2010 and showed that 62 percent of adults over age 65 went below seven. But here's the catch. We found absolutely no difference in how people were treated based on their health. In other words, patients in poor health and at risk for hypoglycemia tended to be treated as aggressively as far healthier patients. This seems to confirm that we have been adhering to a one-size-fits-all approach, despite the risks that it poses to millions of older Americans.

Part of the problem is that there are strong incentives in place to keep the status quo. The diabetes drug industry has a vested interest in selling its products to as many Americans as it can, and has been incredibly successful at doing so. Sales of diabetes drugs in 2013 were about equal to the combined revenue of the National Football League, Major League Baseball and the National Basketball Association. There is nothing wrong with the industry selling its drugs, but it is the job of the medical profession to guide what treatment patients receive. To do this properly, doctors with financial ties to diabetes drug industry shouldn't be writing guidelines on how to use these drugs. At present, this is still common.

Ultimately, changing current paradigms requires that doctors partner with their patients in making decisions about treatment. Patients need to understand that there are different options, with different risks. The goal is not to get a perfect score on a report card, but to weigh these risks to make a good decision.

My patient was terrified at the prospect of having another car wreck — a completely reasonable concern — and we decided to use less insulin and let his sugars run higher, in the eights. It's possible this slightly raises his risk of kidney or eye problems. But this was a risk that he was more than happy to take.

A1C Definition

By Mayo Clinic Staff

The A1C test is a common blood test used to diagnose type 1 and type 2 diabetes and then to gauge how well you're managing your diabetes. The A1C test goes by many other names, including glycated hemoglobin, glycosylated hemoglobin, hemoglobin A1C and HbA1c.

The A1C test result reflects your average blood sugar level for the past two to three months. Specifically, the A1C test measures what percentage of your hemoglobin — a protein in red blood cells that carries oxygen — is coated with sugar (glycated). The higher your A1C level, the poorer your blood sugar control and the higher your risk of diabetes complications.

Why it's done

An international committee of experts from the American Diabetes Association, the European Association for the Study of Diabetes and the International Diabetes Federation recommends that the A1C test be the primary test used to diagnose prediabetes, type 1 diabetes and type 2 diabetes.

After a diabetes diagnosis, the A1C test is used to monitor your diabetes treatment plan. Since the A1C test measures your average blood sugar level for the past two to three months instead of your blood sugar level at a point in time, it is a better reflection of how well your diabetes treatment plan is working overall.

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 24th, 2015 and Thursday October 29th, 2015 at 3:30 p.m. Nicky's has extra parking at the back and it is wheelchair accessible.

Our Christmas Dinner will be 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.

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Annual membership fee: (Jan.- Dec.)

$10 Single; $15 family $_____

My donation to Polio Regina Inc.:* $_____

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Please make cheque payable to: **Polio Regina Inc.** and mail this application form and cheque to:
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