



Christmas 2019

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# Season's Greetings



## Message from the President

*Carole Tiefenbach*



Hello Everyone,  
from sunny,  
beautiful Park  
City, Utah!!

Sadly, another  
year is coming to  
an end in about  
another month.  
Happens every  
year at this time!

There is not a thing we can do about it, except enjoy,  
be grateful for our friends and family, for every day  
we are on this side of the veil!

Fortunately, we have been able to travel at the  
beginning of the year and again in the fall. It is so  
wonderful to be here, in Utah, with so many friends,  
young and old (like us), having a great time together!

We are happy to have missed some of the nastiest  
days in Regina, but we had a few cold days here too,  
just not quite so nasty!

It has been a long time since Feb 6th, when I acquired  
plantar fasciitis on my right heel. What a roller coaster  
it has been! I also tore my meniscus on my left knee  
on July 1st, so literally I had 'not a leg to stand on'!!!  
I would not wish that on any living soul! I guess  
if I had not have torn it on August 20th, it would  
have healed much sooner. However, it is finally on  
the mend now. Lots of pool time, icing and rolling it

constantly, and using my cane has certainly helped,  
along with the best kind of runners for fasciitis, a  
brand called HOKA, a tad expensive but worth the  
money.

We will be checking out of the Marriott tomorrow  
noon (November 15th) and proceeding on to another  
friends home for 5 more sleeps and will be on our  
way home after that.

We have visited so many LDS Temples which are so  
beautiful, magnificent and leaves us totally in awe!

We are happy we will be able to attend the Polio  
Christmas party with all of you again this year. It is  
always a great gathering to end the year with.

Florida will be the next destination for 7-8 weeks, if  
the Lord be willing, then home again for our Spring  
meeting.

Wilf and I both, wish you all a Merry Christmas and  
the happiest, healthiest, New Year ever and may our  
common polio afflictions lessen as we gain more  
knowledge every year, on how to combat the pain  
we all have to endure. May God bless you all and  
may you all be blessed continually, every single day.

Warm regards, with love from  
Carole and Wilf Tiefenbach



# At The Meetings

**May 2019** – Diane Lemon talked about a few items: Research is being done to develop dry vaccines that don't have to be frozen to enable easier access to vaccinations in hot countries.

The importance of choosing the right health advocate. Information and "My Patient Advocate Agreement" form is available at [SafetoAsk.ca](http://SafetoAsk.ca)

Although our annual spring picnic was inside at Nicky's Café we still had a picnic-like atmosphere with hamburgers and all the fixings. We had lots of time to visit and share our experiences with each other.

**September 2019** – Our web master, Peter Haung has moved to Calgary which leaves the position open. David Cotcher volunteered to take over the position.

Diane Lemon informed us that an access card is available for \$30.00 which allows someone with mobility difficulties have an attendant to go with them to various cinemas at no extra charge.

Harriet Zaidman has written a fictional book about PPS. It will be finished by late 2020 and although fiction will use info from interviews with post-polio survivors; Diane Lemon was one of the persons interviewed.

**Open Forum:** Our guest speaker, Sergeant Bryant Westerman from the Regina Police Service, Commercial Crime Unit, gave a presentation on Fraud Prevention. He talked about various ways that fraudsters are able to trick you into giving your information and money to criminals.

The following are some tips that he talked about: If you receive a phone call from a number that you are not familiar with hang up. Never give personal information over the phone. No government agency or bank will ask for money over the phone. If someone phones and asks for information about your credit card, hang up and phone the number on your credit card and ask if they are the ones contacting you.

Be careful with your emails. Beware of phishing emails that appear to be from institutions that you deal with. Check the email address that it came from and if it is different than the institution, delete it. Do not open any links that are in the email. Do not use airport or hotel Wi-Fi to conduct bank or other financial transactions. When using Facebook or other social media platforms, be sure your privacy options are set to be secure.

Be sure you have up to date anti-virus software installed on all devices and if you use a lot of public Wi-Fi it is advisable to subscribe to a VPN.

**VPN** stands for Virtual Private Network. A virtual private network offers a higher degree of protection and privacy as you're surfing the web, whether at home or outside. A VPN creates a secure connection over public networks (such as the Wi-Fi in public transport, hotels, or your favorite café) as well as home networks (like the one provided by your internet service).

By routing your traffic through specialized servers and encrypting your data, VPNs hide your online activity and protect you from the many dangers on the web – from hacker attacks to data selling, identity theft, and much more.

For more information or to report a fraud you can contact:

Canadian Anti-Fraud Centre

[www.antifraudcentre-centreantifraude.ca](http://www.antifraudcentre-centreantifraude.ca)

Phone: 1-888-495-8501 between 10:00 am and 4:45 pm Eastern Time

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Regina Police Service, Commercial Crime Unit

Phone: 306-777-6639

**October 2019** – We decided that spring meetings for 2020 will be held March 26th and April 30th, 2020 at 3:30 p.m. at Nicky's Café. We will decide on the dates and times for the Spring Picnic and fall meetings at future meetings.

**Open Forum:** Our guest speaker, Brenda Schock from the Saskatchewan Health Authority spoke about a Medical Directive, choosing a Proxy, and related information. She handed out "My Life Capsule" pill bottles with sheets to fill out with our medical information to put into our fridge and a magnet to put onto the fridge door so that emergency personnel can access our information in the event that we are unable to speak in an emergency. She also handed out a booklet called "My Voice, Planning in Advance for Health Care Choices" which contains "My Advance Care Plan" to fill out which is your medical directive. A summary of some of the things that Brenda spoke about is printed later in this issue. To get more information or copies of the handouts:

Phone: 1-306-766-5922

Email: [advancecare@rqhealth.ca](mailto:advancecare@rqhealth.ca)

Web Site:

<http://www.rqhealth.ca/quality-transformation/advance-care-planning>

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*The following is copied from the Saskatchewan Health Authority web site on Advance Care Planning*

## What is Advance Care Planning?

Advance Care Planning is sometimes called a living will, advance directive, or health directive.

An Advance Care Plan can be verbal or written. It is legal. You can complete this on your own, with the help of your family, your health care team or your legal advisor. It is the legal set of directions you develop for your medical care if you are too ill or injured to communicate or make decisions. The instructions and information in the plan would only be used to give direction for your treatment if you are not capable of speaking for yourself. (It's intended to be your voice if you are unable to speak for yourself.)

In Saskatchewan, an Advance Care Plan is legal and protected under the Health Care Directives and Substitute Health Care Decision Makers Act, 2015.

All Saskatchewan residents who are 16 and older with capacity can complete an Advance Care Plan and can change or revoke the plan at any time if mentally capable of doing so.

Health Care professionals will help a person complete the order form My Voice for Life-Sustaining Treatment (MVLST). The MVLST will usually be completed on admission to a health care facility or by a health care professional in the community.

The My Voice Booklet has been developed for the public to use in completing their own advance care plan.

To watch a video that explains what Advance Care Planning (Living Wills) is and why it's important to have one, go to:

<http://www.rqhealth.ca/department/advance-care-planning/what-is-advance-care-planning-video>.

The video also shares testimonials from clients that have chosen to prepare an advance care plan.

### What is a Proxy?

When a person is unable to speak for themselves, a Proxy can speak on behalf of the person re their medical wishes.

A Proxy is appointed by the person when they have capacity. The Health Care Directives and Substitute Health Care Decisions Makers Act, 2015 allows a person in Saskatchewan to legally appoint the person of their choice to be their health care decision maker when the person is unable to speak for themselves. The appointed Proxy makes health care decisions for a person, based on the person's expressed wishes when they are unable to express themselves.

The Proxy must be over 18 years of age. The Proxy must be someone the person trusts to be responsible and able to respect the person's opinions, values and wishes for their medical care.

For a copy of the proxy form go to:

[www.rqhealth.ca/service-lines/master/files/9174376\\_8\\_Appointing%20a%20Proxy%202017%20.pdf](http://www.rqhealth.ca/service-lines/master/files/9174376_8_Appointing%20a%20Proxy%202017%20.pdf)



Advance Care Planning is about taking care of your health care business.



**THINK** about your health care choices if you can no longer speak for yourself.

**TALK** about medical options with your family, proxy and health care provider.

**ACT** by sharing your health care wishes with those closest to you.

## The Regina Advance Care Planning Support Team

The Regina Advance Care Planning Support Team is available to provide education on advance care planning to both staff and the community.

Our office is located at Wascana Rehabilitation Centre. You can connect with us by phone at 306-766-5922 or by email at [advancecare@rqhealth.ca](mailto:advancecare@rqhealth.ca).

Web Site:

<http://www.rqhealth.ca/quality-transformation/advance-care-planning>



*Adeline Manz was a long-time member of Polio Regina. The following is her obituary.*

## MANZ, Adeline Stephanie



It is with great sadness but also thankfulness for a long and well lived life, the family announces the passing of our mother, Adeline Manz on Friday, May 31, 2019, at the age of 93. She was predeceased by her husband John, and great-granddaughter

Autumn Manz. Left to cherish her memory are her five children Gord (Lori) Manz, Glen Manz, Donald (Marcia) Manz, Angela (Les) Davis, and Reg (Tammy) Manz. And with wonderful memories she leaves 12 grandchildren Kurt (Kendell) Manz, Dean Manz, Amanda Manz, Andrea (Ray) Paradis, Jordan Manz, Marc (Kendra) Manz, Daric (Lanjell) Manz, Nicholas Davis, Nelson (Jenna) Davis, Alex Davis, Makenzie Manz, Tanner Manz, and Tyson Manz. She also has 13 great-grandchildren. She is also survived by siblings Eleanor Grudnizki, Betty Moore, Norman (Bunty) Manz, Lorraine Roske and Marg Kondra. Memorial service was held Wednesday, June 5, 2019, at the Markinch Town Hall, Markinch, SK at 2:00 p.m. Arrangements in care of Hansen's Funeral Home, Strassbourg, SK.

Published on June 3, 2019



## **‘Milestone’ in Polio Eradication Achieved**

*BBC News 24 October 2019*

**The second of three forms of the polio virus has been eradicated, experts have announced.**

There are three types of the wild polio virus, which, while scientifically different, cause the same symptoms, including paralysis or even death,

The world was declared free of type 2 four years ago - and now the World Health Organization has said type 3 has also been eradicated.

But type 1 is still circulating in Afghanistan and Pakistan.

Polio usually affects children under five. The WHO estimates one in 200 cases leads to irreversible paralysis. Death can occur when breathing muscles are affected by the paralysis.

There is no cure but the polio vaccine protects children for life.

Cases of wild polio have fallen by 99% since 1988.

The declaration type 2 had been wiped out was made in 2015, a full 16 years after the last case was seen in India.

### **‘Not finished’**

It has been seven years since the last case of type 3 polio was detected, in northern Nigeria.

Since then, experts from the Global Commission for the Certification of Poliomyelitis Eradication, of which the WHO is a member, have watched patterns of polio cases to be sure type 3 had been eradicated.

Speaking on World Polio Day, Dr Matshidiso Moeti, the WHO’s regional director for Africa, said: “The eradication of wild polio virus type 3 is a major milestone towards a polio-free world - but we cannot relax.

“Countries must strengthen routine immunisation to protect communities, ramp up routine surveillance so that we are able to detect even the slightest risk of polio re-emerging and ensure the timeliness and

quality of outbreak response in the event that a case is detected.”

Type 1 is now circulating in Afghanistan and Pakistan only. The last case detected case in Nigeria, where it was also endemic, was in 2016.

But Dr Moeti added: “This job is not finished until wild polio virus type 1 is globally eradicated, along with concerning outbreaks of circulating vaccine-derived polio virus.”

Vaccine-derived polio occurs where vaccine coverage is low and there is poor sanitation.

Children who do get immunised are given a weakened form of the polio virus so their body can build up immunity to the disease. But they also then excrete the virus, which can then spread in the community.

There are currently outbreaks of vaccine-derived polio virus in 12 countries: Angola, Benin, Cameroon, Central African Republic, Chad, Democratic Republic of the Congo, Ethiopia, Ghana, Niger, Nigeria, Togo and Zambia.

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## **Pakistan accused of cover-up over fresh polio outbreak**

**Source claims government plans secret vaccinations after 12 children fall prey to disease**

Global development is supported by

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About this content

**Hannah Ellis-Petersen** south Asia correspondent and a reporter

*The Guardian*, Thu 7 Nov 2019 14.35 GMT Last modified on Fri 8 Nov 2019 03.20 GMT

Officials in Pakistan have been accused of covering up an outbreak of the most dangerous strain of polio and planning a covert vaccination programme to contain the disease.

According to a source in Pakistan’s polio eradication programme and documentation seen by the Guardian, a dozen children have been infected with the P2 strain of polio, which causes paralysis and primarily affects those under five.

Dr. Malik Safi, coordinator of the national emergency operation centre of the Pakistan polio eradication programme, confirmed the P2 outbreak, but would not give any further comment.

The P2 strain had previously been eliminated from the country. However, the new cases were allegedly kept hidden from the government and from international donors, including the UK's Department for International Development, under direct instruction from Babar Bin Atta, the prime minister's focal representative on polio eradication, who was last month forced to resign after he was accused of corruption. DfID has donated millions to Pakistan's polio eradication programme.

The alleged cases, which have all resulted in paralysis, have been discovered mainly in Diamer district, with one in the capital, Islamabad.

Under Pakistani law, every new case of polio in the country has to be officially registered with the government, which then alerts international health bodies. "But to hide their negligence and their poor performance, Babar Bin Atta decided not disclose the cases to anyone," said the source.

The re-emergence of P2 would not only be a dramatic step back in Pakistan's fight against the polio, it would also be symptomatic of what those in the programme have described as "terrible mismanagement" under Bin Atta.

Alongside Afghanistan, Pakistan is one of only two countries in the world that has not entirely eradicated polio. It was a key milestone in 2014, when Pakistan officially declared it had entirely eradicated P2 polio.

Polio exists in three different strands, P1, P2, and P3, with P2 notorious as the most contagious and most vicious in its impact on those infected.

According to the source within the programme, the renewed outbreak of the P2 strand came from a mismanagement of vaccines, which carry a live strain of the disease to create immunity.

After the strand was eliminated from Pakistan five years ago, all P2 vaccines should have been collected from hospitals and clinics and not used. However, it appears a P2 vaccine was administered accidentally

and a child became a carrier for the disease. Tests on the new cases allegedly show the children are all carrying a vaccine-derived form of the disease .

"Somewhere, somebody has inaccurately used this vaccine and because of this negligence ... this virus was brought back into the environment and our children are again getting infected with P2," alleged the source.

However, it is understood that, instead of publicly declaring the renewed outbreak and beginning a public vaccination campaign, a "secret" vaccination campaign will begin on Monday in Rawalpindi and surrounding cities in an attempt at containment. It is understood that only senior members of the polio programme are aware of the P2 campaign, with others – even those who will be administering the vaccines – led to believe it is a standard P1 and P3 polio vaccination programme.

This P2 outbreak can only be contained if they do a quality vaccination campaign, and how can you do a quality campaign if you are carrying it out in secret, without any awareness or accountability?" said the source.

"If anything goes wrong and this P2 polio spreads throughout the whole country, who will take responsibility? Will they just keep telling more lies to cover up their mistakes and put more children at risk?"

Since 2018, there has been an "alarming" rise in polio cases in Pakistan, according to experts, with 77 official cases this year. Senator Ayesha Raza Farooq, who served as the prime minister's focal person on polio eradication from November 2013 to August 2018, said Bin Atta had "ruined" the programme through corruption and mismanagement.

Farooq accused the prime minister, Imran Khan, of refusing to listen to complaints against Bin Atta for the past 10 months. "PM Khan did not take heed to the programme and ignored the complaints which were coming to him against Babar Bin Atta," she said. "They covered up the refusals and they allegedly used fake markers on kids' to show they were vaccinated who actually were not. The damage that has been done to the programme has literally reversed many of our achievements."

## Donors Pledge \$2.6 Billion for ‘Last Mile’ of Polio Eradication

*Reuters, November 19, 2019, 7:02 AM EST*

*Filed under PMN Health*

LONDON — Donor governments and philanthropists pledged \$2.6 billion on Tuesday to help fund a worldwide polio eradication plan that has taken decades to reach what global health specialists say is now the “last mile.”

The funding – almost of half of which came in a single donation from the Bill & Melinda Gates Foundation – will be used to immunize 450 million children against polio each year, the World Health Organization (WHO) said in a statement.

WHO Director-General Tedros Adhanom Ghebreyesus said that by seeking to reach “every last child” with vaccines against the crippling viral disease, the Global Polio Eradication Initiative (GPEI) is coming ever closer to achieving a polio-free world.

The WHO last month announced an “historic step” in the fight to wipe out polio, certifying that the second of the three types of the polio virus had been eradicated globally.

Global polio cases have been cut by more than 99% since 1988, but the type 1 polio virus is still endemic in Pakistan and Afghanistan, where it has infected 102 people this year. That is a resurgence from a record low global annual figure of 22 cases in 2017.

Polio invades the nervous system and can cause irreversible paralysis within hours. It cannot be cured, but it can be prevented by vaccination – and a dramatic reduction in cases worldwide in recent decades has been due to intense national and regional immunization campaigns for babies and children.

The \$2.6 billion pledge will part fund the GPEI’s 2019-2023 “endgame strategy.” A total of \$3.27 billion is needed to fully implement the plan, the WHO said.

Donors made their pledges at a “Reaching the Last Mile” polio conference in Abu Dhabi. The funding

includes \$1.08 billion from the Gates Foundation, around \$514 million from Britain, \$215 million from the United States, \$160 million from Pakistan and \$150 million from the charity Rotary International.

*(National Post -Reporting by Kate Kelland; Editing by Pravin Char)*



*The following are posts reprinted from Dr. Bruno’s “Bruno Bytes”*

### On the Topic of the Three Types of Wild Polio

**Question:** If a person had polio can that person get it again or be a carrier? Is it true that are three polioviruses causing different types of polio?  
**Dr. Bruno’s Response:** Get polio more than once? Yes. There are three polioviruses. You could get Type I, Type II and Type III. If you’d had a given type of poliovirus you’d have enough antibodies (if not immunocompromised) not to be a carrier of that poliovirus and shed virus if you were infected again, nor would you get symptoms. Is it true that each of the three polioviruses caused three different types of polio? No. But there has always been confusion about there being “three types of polio: bulbar, spinal and bulbar-spinal.”

Genetically, there are three different types of poliovirus as described above. Each type therefore requires a different polio vaccine made from each of the three viruses to generate the specific antibody’s needed to counteract each.

Anatomically, there aren’t three types of polio. Everyone who had paralytic polio had some degree of damage to their spinal cord and brainstem. So everyone who had paralytic polio, and many who had polio but showed no symptoms at all (“non-paralytic” polio), had bulbar and spinal polio. This is all covered in detail in **The Polio Paradox**.

Excerpt from the Polio Paradox (page 22):

“There are three different types – each named for the



location where it was found, wither in a city or inside a person: Brunhilde, Lansing and Leon. The three types are different because your immune system makes a different antibody for each. But, they are also different in terms of how common they are and their ability to cause harm.

- Almost all of history's polio epidemics have been the result of Type 1 poliovirus, which caused leg, arm and sometimes breathing muscle paralysis.

- The Type 2 virus seems to have been least likely to cause paralysis but may have damaged the "stem" at the bottom of the brain, just above the spinal cord and was responsible for huge outbreaks of "nonparalytic" polio and something called the "Summer Grippe" (See Chapter 17).

- Type 3 poliovirus, the most rare, also caused leg and arm paralysis but was most likely to produced so-called "bulbar" polio, in which the bulb or stem of the brain was severely damaged. This damage caused difficulties with swallowing, breathing and blood pressure that were sometimes fatal."

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## On the topic of Exercise Causing Permanent Paralysis (4/28/2019)

**Original Post:** If you are overusing your muscles, would that lead to eventually paralysis of those muscles, or does overuse lead to more and more pain/weakness but never paralysis?

**Dr. Bruno's Response:** After nearly 40 years and 7000+ polio survivors I have never seen overuse cause permanent paralysis. In the first survey we did of polio survivors in 1985, the leading cause of muscle weakness was exercise and overuse.

**Additional Question:** The next question to is "to what degree do muscles weaken"? Is it "I could bench 200 lbs one day and only 100 lbs a year later," or is it more significant (200 lbs down to 20 lbs)?

**Dr. Bruno's Additional Response:** It's more like you could always stand up on your own, then you had to use your arms to get out of a chair and then, even when you got out of the chair using your weakening arms, your legs won't hold you up.

## Should Polio Survivors Exercise? No Way!

*Richard Bruno-Wednesday, November 6, 2019  
by Dr. Richard L. Bruno*

**Question:** In January I shoveled snow and my left leg became very weak. My knee buckled twice but I caught myself before I fell. I went to my doctor and he sent me right to physical therapy. In the first session I was on the treadmill for 10 minutes, on the bike for 5 and I did straight leg raises with weights around my ankles. I barely made it home, where I fell to the kitchen floor. My legs are even weaker now and they are always burning. Don't polio survivors need exercise to make weak muscles stronger?

**Dr. Bruno's Response:** Your body is answering that question for you, but let me tell you about the research on exercise in polio survivors. There have only been about half a dozen small studies that tested around 12 subjects each. And although 90% of the subjects were said to have "Post-Polio Syndrome" or reported new muscle weakness, their legs were stronger than yours.

Subjects were able to ride a bike for 5 minutes and then straighten their legs many times while a weight was attached to the ankles 2 to 4 times a week for from six weeks to two years—something you couldn't do one time. The studies tested polio survivors' ability to strengthen their quadriceps muscle, the muscle in the front of your upper leg that allows you to lift your lower leg up off the floor while you're sitting and to "lock" your knee. The quadriceps is the muscle that gave out when you fell in the kitchen.

The studies differed in the way exercises were performed. Two studies asked polio survivors to limit the number of leg lifts if they felt fatigue, told them to rest between bouts of exercise and increased the amount of weight lifted only if there was no "excessive fatigue." Other studies described their exercise regime as "high-intensity," "heavy resistance," or "aggressive." Two studies required polio survivors do five minutes on an exercise bicycle before they did as many as 30 leg lifts three times each week. In the most aggressive study polio



survivors did five minutes on the bicycle followed by a 60 minute exercise class twice a week for 5 months! A polio survivor who is able to do that kind of exercise *doesn't* have PPS.

Clearly, the subjects in the studies had more strength, more endurance, more ability to function and fewer symptoms than you do or do the patients we treat. Still, when you read the researchers' conclusions it sounds like exercise is just the thing to restore muscle strength in polio survivors with PPS: "a supervised training program can lead to significant gains in strength."

Unfortunately, when you look at the study's findings, the benefits of exercise are far from clear. Only 53% of those who exercised had an increase in leg muscle strength of about 26%. Twenty-six percent of subjects had no change in strength while 21% had a decrease in strength of about 10%. So, more often than not, exercise either had no effect or actually decreased muscle strength.

But there's more. Well, actually less. Only three studies asked whether exercise had an impact on polio survivors' ability to function in their daily lives. In one study where exercise was limited by fatigue, there was no measurable change in muscle strength over 2 years, although half of the subjects thought their walking and stair climbing had improved. In one aggressive study there was a 29% muscle strength increase, no improvement in subjects' ability to do their daily activities, but an increase in muscle fatigue of from 150% to 300%! Muscle fatigue also increased by 21% in another aggressive study in which strength increased by 36%. You have to ask what good comes from any small increases in muscle strength that are not related to improved functional ability but are related to muscle fatigue that increases more than strength does.

Dr. Alan McComas' performed a study showing that polio survivors who are not treating their muscle weakness and were getting weaker lost 7% of their motor neurons each year. McComas concluded that "polio survivors should not engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking." Muscles weakness is a sign of neurons failing and dying.

I know that you were taught to "use it or lose it" and to exercise until you "feel the burn."

When you feel the burn you are burning out your neurons.

What's the bottom line regarding exercise to strengthen newly weakened muscles? **Don't.**



## On the topic of Supplements

(8/1/2019)

**Dr. Bruno's Original Post: SUPPLEMENTS:** Don't help, can hurt, cost a lot and you may not even be getting the supplement whose name is on the bottle. Clearly, you have to be very careful in considering the claims about dietary supplements, be they herbal remedies or vitamins. For example, "PP Tabs" from Europe, "a completely guaranteed and clinically proven herbal treatment for Post-Polio Syndrome." (By the way, PP Tabs is out of business.) The PP Tab site says, "Thousands of patients have been successfully treated with PP Tab over the past few years. Had the effectiveness of PP Tab not been proven beyond any doubt, it would not be possible for us to make such a bold claim. To download the summary of a clinical research study on the effectiveness of PP Tab, please click the link below." I clicked, and this came up: "Clinical Study soon to be posted." How can companies get away with such claims?" Unfortunately, manufacturers of herbal "treatments" can get away with saying whatever they want because there is no legal restriction on their claims. The PP Tab site (<http://pp-tab.com>) says that the "Tabs" contain ingredients "blended together in a specific proportion to fight and treat Post-Polio Syndrome effectively." What are the ingredients? They're magnesium and zinc, plus eggshell calcium, sulphur, substituted olive oil and turmeric -- an Asian spice and yellow food-coloring agent. The company claims that their PP Tab treatment is very fast, and obvious results can be seen in 40 days, although "a complete course of treatment lasts three months." So,

it will cost you nearly \$240 to get what the company hypes as the “world’s most relied upon and clinically proven...safe and effective...natural treatment for Post-Polio Syndrome,” which has “absolutely no alternative to its unique formula.”

But if you search the ingredients in PP Tabs, you’ll discover the unique formula for treating post-polio syndrome isn’t unique at all. The same company sells a variety of “Tabs,” all having the identical formula: Clearotab completely guaranteed and clinically, proven herbal treatment for Dark Circles and Bags Under Eyes; Raynotab, to fight and treat raynauds disease effectively; Syrotab, guaranteed to improve syringomyelia; Guillatab, “clinically proven to treat Guillain-Barre Syndrome successfully.” As with PP Tab, the other advertisements say that you can download a summary of a clinical study, but clicking gives the same message: “Clinical study soon to be posted.” For those wanting to spend less than \$240 for PP Tab’s “proven beyond any doubt” treatment for PPS, for only \$89.95 polio survivors can “improve all symptoms, prevent and treat later complications, correct imbalance, adjust the immune system and most importantly to boost energy and strong body for better health and quality of life” with Hsin Kuang’s Remedy 010-016. This Chinese curative, blended specially for you, contains six herbs plus two dried worms and the dried body of a scorpion. Remedy 010-016 is said to be “without any side effects” and with “Overall Success Rate 100%” (as tested on 19 polio survivors). (And with two dried worms and dried body of a scorpion? Yum! ) Clearly, you have to be very careful considering the claims about dietary supplements, be they herbal remedies or vitamins. The FDA considers herbal remedies as “food additives” (like turmeric) that don’t have to go through the lengthy and expensive process that proves they are drugs, i.e., that they are effective in treating disease. That’s why the FDA requires a supplement’s label to state that it is not intended to “diagnose, treat, cure or prevent any disease.” However, there’s a more dangerous problem than unsubstantiated claims. Supplements are required by the FDA to be safe -- and some may not be. Ginko biloba, a common herbal remedy, can decrease the effectiveness of anti-seizure drugs and has blood-thinning properties, so it shouldn’t be used if you’re taking anticoagulants like coumadin. Conversely, another “remedy,”

Coenzyme Q10, may decrease the effectiveness of blood-thinning medications. Even vitamins can be dangerous. Too much vitamin A can cause symptoms identical to PPS -- fatigue, muscle and joint pain -- and even can be fatal. Unfortunately, there’s still no “magic pill” to treat, let alone cure, PPS. If you want to take something to reduce PPS symptoms, try a proven dietary “supplement,” having protein at each meal. Please see the “Post-Polio Protein Diet” in the Articles Section of the Encyclopedia of Polio and PPS (under “Diet”). Protein has been “proven beyond any doubt” to PPS symptoms and is a lot cheaper (and tastier) than herbs, worms and scorpions...or ingredients first found in jellyfish!

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## On the topic of Gabapentin for Pain (5/21/2019)

Dr. Bruno’s Original Post: Gabapentin, et al: Do they even provide a placebo effect?

“In many well-controlled studies they found there was less than a one-point difference on the 10-point pain scale between patients taking the drug versus a placebo, a difference often clinically meaningless. Despite the limited evidence of benefit, Dr. Johansen found that the number of people taking gabapentinoids more than tripled from 2002 to 2015.”

### Millions Take Gabapentin for Pain But There’s Scant Evidence It Works.

*By Jane E. Brody N.Y. Times May 20, 2019*

“There is very little data to justify how these drugs are being used and why they should be in the top 10 in sales,” a researcher said.

One of the most widely prescribed prescription drugs, gabapentin, is being taken by millions of patients despite little or no evidence that it can relieve their pain. In 2006, I wrote about gabapentin after discovering accidentally that it could counter hot flashes. The drug was initially approved 25 years ago to treat seizure disorders, but it is now commonly prescribed off-label to treat all kinds of pain, acute and chronic, in addition to hot flashes, chronic cough and a host of other medical problems.

The F.D.A. approves a drug for specific uses and doses if the company demonstrates it is safe and effective for its intended uses, and its benefits outweigh any potential risks. Off-label means that a medical provider can legally prescribe any drug that has been approved by the Food and Drug Administration for any condition, not just the ones for which it was approved. This can leave patients at the mercy of what their doctors think is helpful.

Thus, it can become a patient's job to try to determine whether a medication prescribed off-label is both safe and effective for their particular condition. This is no easy task even for well-educated doctors, let alone for desperate patients in pain.

Two doctors recently reviewed published evidence for the benefits and risks of off-label use of gabapentin (originally sold under the trade name Neurontin) and its brand-name cousin Lyrica (pregabalin) for treating all kinds of pain. (There is now also a third drug, gabapentin encarbil, sold as Horizant, approved only for restless leg syndrome and postherpetic neuralgia, which can follow a shingles outbreak.)

The reviewers, Dr. Christopher W. Goodman and Allan S. Brett of the University of South Carolina School of Medicine, found the drugs, called gabapentinoids, wanting in most cases for which they are currently being prescribed. As Dr. Goodman said in an interview, "There is very little data to justify how these drugs are being used and why they should be in the top 10 in sales. Patients and physicians should understand that the drugs have limited evidence to support their use for many conditions, and there can be some harmful side effects, like somnolence, dizziness and difficulty walking." Furthermore, for patients prone to substance use disorders, like an opioid addiction, the gabapentinoids, although they are not opioids, are potentially addictive, he said.

The gabapentinoids are symbolic of three currently challenging problems in the practice of medicine: a deadly national epidemic of opioid addiction prompting doctors to seek alternative drugs for pain; the limited training in pain management received by most doctors; and the influence of aggressive and sometimes illegal promotion of prescription drugs, including through direct-to-consumer advertising.

Gabapentin and Lyrica, both sold by Pfizer, have been approved by the Food and Drug Administration to treat only four debilitating pain problems: postherpetic neuralgia, diabetic neuropathy, fibromyalgia and spinal cord injury. Even for these approved uses, the evidence for relief offered by the drugs is hardly dramatic, Drs. Goodman and Brett reported in JAMA Internal Medicine online.

In many well-controlled studies they found there was less than a one-point difference on the 10-point pain scale between patients taking the drug versus a placebo, a difference often clinically meaningless. For example, among 209 patients with sciatica, Lyrica did not significantly reduce the intensity of leg pain when compared with a placebo, and dizziness was more commonly reported by the 108 patients who took the drug. But when patients complain of pain related to conditions ranging from sciatica and osteoarthritis to foot pain and migraine, clinicians often reach for the prescription pad and order either gabapentin or the more costly Lyrica. Following the approval of Neurontin, its producer at the time, Warner-Lambert, engaged in what the government determined was an illegal marketing campaign that resulted in sales exceeding \$2 billion a year before its patent expired in 2004. Still, the campaign succeeded in bringing gabapentin to the attention of many doctors who treat patients with persistent life-disrupting pain.

It's not that there are no other alternatives to opioids to treat chronic pain, among them physical therapy, cognitive behavioral therapy, hypnosis and mindfulness training. But practicing clinicians may be unaware of the options, most of which require more effort for the doctor than writing a drug prescription and are not as easy or accessible for patients as swallowing a pill. As Dr. Michael E. Johansen, a family doctor in Columbus, Ohio, put it, "I use gabapentin clinically and try to stay close to the approved indications, but occasionally we run out of options when faced with patients who hurt. It's rare that these drugs eliminate pain, and I don't tell patients their pain will go away. If there's any benefit, it's probably marginal."

Despite the limited evidence of benefit, in a study published in JAMA Internal Medicine in February,



Dr. Johansen found that the number of people taking gabapentinoids more than tripled from 2002 to 2015, with more than four in five taking the inexpensive generic, gabapentin.

In 2016, 64 million prescriptions for gabapentin were dispensed, up from 39 million in 2012, Drs. Goodman and Brett reported in *The New England Journal of Medicine*. They believe that the opioid epidemic partly fueled this increase. “While working in inpatient and outpatient settings,” they wrote, “we have observed that clinicians are increasingly prescribing gabapentin and pregabalin for almost any type of pain.”

Dr. Johansen cited several serious concerns about overuse of gabapentinoids, including “a dearth of longterm safety data, small effect sizes, concern for increased risk of overdose in combination with opioid use, and high rates of off-label prescribing, which are associated with high rates of adverse effects.”

Contributing to the frequent misuse of gabapentinoids is how doctors interpret the term “neuropathic pain” for which the drugs are commonly prescribed. It is defined as pain caused by a lesion or disease of the nervous system, leading clinicians to assume that if a drug is effective for one type of neuropathic pain, it is effective for all types, regardless of the underlying cause, Drs. Goodman and Brett suggested.

Dr. Johansen pointed out that “there is no recipe book” for treating pain with gabapentinoids. “Doctors need to work with one patient at a time and figure out what works and what doesn’t work,” he said. He noted that many times pain resolves with “the tincture of time” but patients and doctors may attribute improvement to the prescribed drug. For those taking a gabapentinoid, he suggested that patients’ doctors readdress its use after two or three months.

But, Dr. Goodman cautioned against going off the drug cold turkey because there can be unpleasant withdrawal symptoms.

## Teacher Arrested at Airport - Held in Isolation

A secondary school teacher was arrested today at Ottawa’s McDonald-Cartier Airport as he attempted to board international flight while in possession of a ruler, a protractor, a pair of compasses, a slide-rule and a calculator.

At a press conference, a Canadian Border Control spokesman said he believes him to be a member of the notorious extremist Al-Gebra movement. He did not identify the man, who has been charged by the RCMP with carrying weapons of maths instruction.

‘Al-Gebra can be a problem for all of us’, the Spokesman said. ‘They derive solutions by means and extremes, and sometimes go off on tangents in search of absolute values.

They maintain secrecy by using secret codenames such “X” and “Y” and refer to themselves as “unknowns” but we have determined that they belong to a common denominator of the axis of medieval with coordinates in every country.’

As the Greek Philosopher Isosceles used to say, “There are three sides to every triangle”.

When asked to comment on the arrest, Prime Minister Justin Trudeau said - “If God had wanted us to have better weapons of maths instruction, He would have given us more fingers and toes.” Fellow Liberal colleagues told reporters they could not recall a more intelligent or profound statement by the Prime Minister.







## Trauma and Illness as Precipitants of Post-Polio Sequelae

*Post-Polio Sequelae Monograph Series. NY: random harvest, 2017*

Dr. Richard L. Bruno, HD, PhD

Director, International Centre Polio Education

[www.postpolioinfo.com](http://www.postpolioinfo.com)

I have often been asked to be an expert witness for a polio survivor who's been rear-ended in their car, hit by a bus, taken a header down some stairs or simply slipped and fell. Regardless of the type of accident, the lawyer always asks the same question: Can a traumatic event trigger Post-Polio Sequelae? And regardless of the type of accident, my answer is always the same: Yes...and no. PPS is not a disease that is just waiting inside polio survivors for a trigger to set it loose to wreak havoc throughout the body. So trauma can't trigger a disease that is not there.

But our 1985 National Survey did show that PPS symptoms are caused by physically or emotionally stressing the poliovirus-damaged motor nerves that remained after survivors' original bout with polio. Many polio survivors have been able to function for 40 years with about half the spinal motor nerves of someone who didn't have polio. So breaking a leg in a fall, having major surgery -- even a whiplash injury -- could sufficiently stress the remaining polio-damaged motor neurons to "blow a fuse." When those fuses blow, neurons function less well and muscle weakness, fatigue, pain can result.

Many polio survivors are terrified about losing function after trauma. One survivor said, "I am afraid if I fall and break something I will never walk again." Fear also causes polio survivors to postpone even necessary surgery because, as one survivor put it, "I know I'll never survive the anesthetic. I will spend the rest of my days in an iron lung."

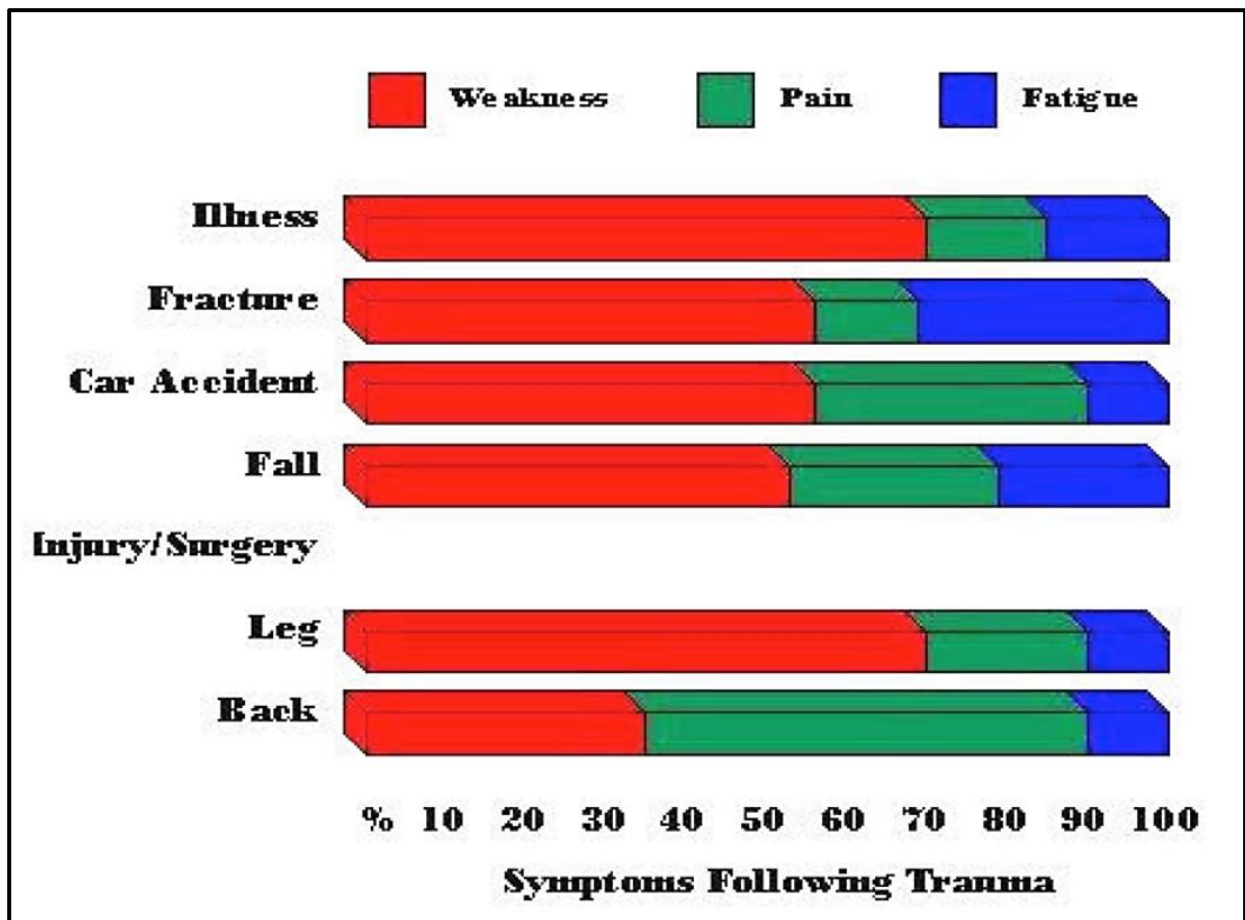
Because of the fear that an injury or surgery could trigger PPS symptoms, we wanted to find out just how many of our patients actually experienced new symptoms after trauma, what those symptoms were, whether they spread throughout the body and whether they were irreversible or treatable.

### SURGERY, SPILLS AND OTHER ILLS.

We reviewed the histories of 244 consecutive polio survivors evaluated by us who had no other conditions that might cause new fatigue, weakness or pain. Of those patients, 44 (18%) said that their PPS began after a traumatic event. The typical patient was 59 years old and had polio at age 8 in the early 1940's. There were as many men as women reporting these *post-traumatic* PPS.

The traumas that preceded new symptoms included medical illnesses and surgeries (pneumonia, viral infection, hysterectomy, mastectomy with chemotherapy, pregnancy), fractures of the ankle, leg or hip, falls, auto accidents, and injury or surgery to the leg (ankle sprains, knee surgery, hip or knee replacement) or the back (herniated discs, laminectomies, spinal fusions) (see graph). The most common injury was to the leg (71% of patients) while 26% had back injuries. Regardless of the type of trauma or location of the injury, the most common symptom reported was new muscle weakness (55% of patients) followed by pain (34%) and fatigue (11%).

There was no evidence that new symptoms began in an injured area and then "spread" throughout the body. Seventy-one percent of patients had new symptoms only in the body area that had been injured, while 26% had symptoms in the injured area plus one other nearby location. For example, 40% of those who injured one leg developed weakness or pain in the other leg. This is a common problem for polio survivors, who compensate for injury to one part of the body by overusing another part whose nerves were also damaged by the poliovirus. Only 5% of patients developed symptoms in more than two body areas. One patient who had a hip replacement reported "loss of muscle tone all over," while another who had been in a coma after an auto accident reported weakness in all of his muscles. Two patients who had had fractures, two with back injuries and one with an ankle injury reported new fatigue. However, no patient reported that their trauma "triggered" symptoms unrelated to the injury, such as arm weakness after breaking a leg or difficulty swallowing following a knee replacement.



## CAN POST-TRAUMATIC PPS BE TREATED?

All of the clinical experience and research on treating non-traumatic PPS supports one conclusion: If patients decrease physical and emotional stress their symptoms will at very least stop progressing and typically will get noticeably better. Does this hold true for post-traumatic PPS? There's good news and bad news.

The bad news is that the majority (63%) of patients with post-traumatic symptoms refused treatment altogether or refused to complete therapy for their symptoms; more than *twice* as many post-traumatic PPS patients actually quit therapy. What might cause this? Of those who had a psychiatric diagnosis 77% refused therapy, versus 53% of those without psychological problems. The most frequent psychiatric problem was a major depressive episode; 89% of those who were

depressed refused therapy. Depression has been identified before as a significant cause of therapy refusal in polio survivors and highlights how important it is for psychological problems to be identified and treated if therapies for PPS are even to begin.

The good news is that 86% of patients -- regardless of the type of trauma or severity of their injuries -- had significant reductions in pain, fatigue and muscle weakness after complying with therapies known to be effective in treating PPS: Reducing physical and emotional stress, using appropriate assistive devices, energy conservation, adequate rest and pacing activities.

The remaining patients experienced a reduction in some symptoms, especially pain, but continued to report muscle weakness or fatigue. Two patients who did not stop strenuous work or recreational activities reported slowly increasing muscle weakness and pain over several years. One patient who had been thrown to the floor of a van in which she was riding reported that muscle strength and endurance in her legs increased only slightly after therapy even though her severe back pain had been eliminated. It is noteworthy that this patient had completely recovered from two previous traumas: A fall early that fractured her lower right leg and another auto accident seven years before that herniated a disc. This patient's ability to recover from two previous traumas is also good news. For each of our patients who reported PPS symptoms after a trauma there was at least one other patient who had had the same trauma but did *not* develop PPS. So while trauma can be sufficient to cause PPS, PPS do not necessarily "come after a fall."

#### "THE GOLDEN RULE"

These findings in our patients should put polio survivors' minds at ease. Neither major surgery nor even a fall that causes a fracture will necessarily push polio survivors down a slippery slope toward untreatable symptoms let alone total disability. Still, caution must be exercised since damaged motor neurons make polio survivors more susceptible to problems that typically do follow trauma. A leg that has been in a cast for months can become weak, as can the opposite leg that has had to take up the slack for its damaged partner. And bed rest after surgery can more easily cause deconditioning and fatigue in polio survivors.

However, post-traumatic symptoms in polio survivors should not be treated aggressively as they often are in those who didn't have polio. All PPS symptoms need to be treated *carefully and slowly*. Polio survivors and their therapists should not assume that a leg weakened after being in a cast has merely "been resting too long" and will respond to an aggressive program of weight lifting. Polio survivors who have had surgery should not be rushed out of bed to prevent deconditioning, because the lingering effects of anesthetic and post-operative pain are more likely to cause falls than to prevent fatigue.

Regardless of the cause of PPS symptoms the "Golden Rule" for polio survivors always applies: If an activity causes fatigue, weakness or pain, don't do it! Doctors, nurses, and therapists must listen carefully to their patients -- and polio survivors must listen carefully to their own bodies -- to determine how much exercise or therapy causes fatigue, weakness or pain, and to *stop* before those symptoms appear, so that therapy for PPS does not become just another type of trauma. The experience of our patients is that post-traumatic PPS are treatable if polio survivors follow through with therapy.

But even more important is that many traumas can be avoided, like falls and fractures caused by compulsive overdoing, ignoring new muscle weakness and refusing to use a needed brace, cane or crutch. For polio survivors physical overexertion, like pride, does goeth before a fall.

## 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 26, 2020, and Thursday April 30, 2020 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](mailto: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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*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.*

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## 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 6, 2020*

\$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.)