

# POLIO



# POST

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## **Presidents Report September, 2022**

Welcome to Fall. Summer has flown by, first with the rain and more rain, and then great temperatures. I have become heavily involved in post-polio support groups over the summer and have learned so much on the disease of polio and especially the late effects of polio that we term “Post-Polio Syndrome”

It has been so helpful to attend calls across Canada, the US, and Australia, to learn how PPS has affected different individuals and the things they have done to cope with the impact of PPS in their life. During these sessions people share their challenges, their exciting family moments, mobility aids, sleep aids, pain coping methods, information sheets to share with medical professionals and ways to mitigate the progression of fatigue, stress, and increased paralysis. These virtual support groups sponsored by March of Dimes and Polio Australia are easy to access with technical assistance provided at no cost where required. Most groups are aging like ours and have had to curtail meetings in person due to the aging and increasing mobility challenges of their members. PPN Manitoba faces similar challenges, and it is encouraging to see so many of our members have chosen to attend and share in these virtual support groups. Many of these sessions are focused on a single topic (e.g., pain medication, safe exercise, coping with surgeries, sleeping, fatigue, accessible travel, safety in the home, electronic aids, mobility devices and presentations on polio and PPS by professionals that speak in an easily understandable way). It has been amazing to hear so many people describe how they recovered from polio and experienced no issues at all during their adult life with weakness, fatigue, swallowing or breathing until sudden onset in their 60’s and 70’s. The importance of sharing this message became apparent to me as I listened to the impact PPS was having and the different strategies that attendees were using in their own lives.

Over the summer with the re-emergence of paralysis from polio and the decline in vaccinations in western countries as a result of access to medical care during the pandemic, mis-information about vaccines being shared on social media by the anti-vax cult, and the perceived lack of necessity in young families as they have not heard about polio nor the impact it can have in their lives and their children’s lives if they remain un-vaccinated. Polio has been detected in wastewater in London, Israel, New York State, New York City and in Upper New York State where an unvaccinated man in his early twenties has been paralyzed by polio. New cases of paralytic polio have been identified in children in Ukraine, Israel, Nigeria and Malawi and polio remains endemic in Pakistan

and Afghanistan. As each case of paralysis is identified we are reminded that 100's more have been infected and continue to transmit the virus for 6-8 weeks after the initial infection even when no symptoms are experienced.

I have been contacted by numerous news sites and agencies, Rotarian clubs, disability podcasts, and even the Executive Director of "Project Child Malawi" to share how this news impacts me and other survivors of polio. These have included: CBC News Online, CBC National both radio (French and English) and TV, Ginella Massa and the Current on CBC Radio as well as CJOB and CBC Winnipeg morning show with Marcy Markusa, and international TV on the Al-Jazeera network. These interactions and interviews plus my own personal mobility and fatigue challenges brought on by the increased impact of post-polio syndrome have made for an interesting and busy summer. As my personal mobility becomes more challenging, I have been addressing accessibility challenges that I have encountered trying to use washrooms in parks and restaurants, trying to access buildings and trying to swim in pools and lakes. Over the last 8 weeks I have spent many hours in conversation about these issues and what can be done to improve them with city officials, pool managers, lifeguards, business owners and my city councilor. I have been surprised both by the lack of accessibility and the willingness to improve these things. It's important that we raise our concerns with the appropriate people to get these issues addressed not just for our members but for everyone that has accessibility issues. Many people around the world are encountering both the late effects of polio that they never expected and even new cases of paralysis

I look forward to working with our members as we deliver our message over the coming months especially as World Polio Day approaches October 24. October 5th I have been asked to make a presentation via Zoom to the Rotary Club of Winnipeg. All our members have been invited to attend to join in the presentation of your own life experience, to answer questions, or just to watch. I hope you will join me. Please send an email to [postpolionetwork@gmail.com](mailto:postpolionetwork@gmail.com) and I will have the organizer add you to the list.

Our first meeting this fall will be September 27<sup>th</sup> at the Caboto Centre and will include a presentation on safe exercise and arthritis issues with our presenter Bonnie Hopps. I would like to thank Lorna for arranging this presentation. I look forward to seeing you soon.

## **Seniors and Long Term Care**

### **June 3 2022 (Hon. Scott Johnston)**

Excerpt From Senior Scope, June 10 2022 Issue

**M**anitoba Seniors are a high priority for the Manitoba government, which is why Premier Heather Stefanson has established Seniors and Long-Term Care department to advocate for seniors' issues and improve the quality of life of all older Manitobans. It was announced as a part of Budget 2022 to support that commitment, our government is investing nearly \$20 million to develop a new plan for older Manitobans. An extensive public and stakeholder engagement process is well underway to hear from Manitobans, which will help guide this plan. The core tenets of the future plan will be:

- to determine the best plans to help older Manitobans remain safely in their own homes for as long as possible,
- to honour their dignity and to ensure they can live as independently as they desire.

Older Manitobans are among the fastest growing segments of our population, and as we age, our social services, amenities, access to information and resources must meet the changing needs of this population. Over 6000 people have already participated in the online part of the consultations on Manitoba's public engagement platform, EngageMB We need your perspectives on how we can make this possible. The first public survey is available at <https://engagemb.ca/building-a-plan-for-older-manitobans>. Please visit the site and share your thoughts on the experiences. Hon. Scott Johnston is the MLA for Assiniboia and the Minister of Seniors and Long-Term Care.

# Members Page

## Upcoming Events

### 1. September General Meeting

DATE: **September 27<sup>th</sup>**, 2022

LOCATION: Caboto Centre  
1055 Wilkes Ave; WPG

TIME: 12:30 p.m. – 2:30 p.m.

SPEAKER; Bonnie Hopps

TOPIC: Benefits of Safe Exercising

TIME: 12:30 p.m. – 2:30 p.m.

### 2. October General Meeting

DATE: **October 25<sup>th</sup>**, 2022

LOCATION: Caboto Centre  
1055 Wilkes Ave; WPG

TIME: 12:30 p.m. – 2:30 p.m.

SPEAKER; TBA

### 3. November WINTER CELEBRATION LUNCHEON DATE:

**November 25<sup>th</sup>**, 2022

LOCATION: Caboto Centre  
1055 Wilkes Ave; WPG

TIME: 12:30 p.m. – 2:30 p.m.

Cost: Members Free Guests: \$10

**RESERVATIONS REQUIRED**

Before Nov. 15th, 2022

TELE: 204-975-3037

EMAIL: [postpolionet-ork@gmail.com](mailto:postpolionet-ork@gmail.com)

## DO I STILL NEED TO BE VACCINATED AGAINST POLIO IF??

By Mike Kossove, Professor Emeritus, Adjunct Professor of Microbiology, Touro University, School of Health Sciences, NY; 8/10/22

1. I had polio, recovered and don't remember or was never vaccinated.

There are three types of polioviruses: Types 1, 2 & 3. You may have had one of these, any combination of the three, or all three. Ask your doctor for a Polio Titer Blood Test. It will measure your polio antibody levels. Unfortunately, **today** they only test for Types 1 and 3. If the test comes back with antibodies for both, speak with your doctor about getting immunized. Back in the day, those who were immunized with Salk or Sabin vaccines, received all 3 types of poliovirus.

2. I had polio, recovered, and was vaccinated with Salk or Sabin.

No, you have lifetime antibody levels for all 3 types of polio.

3. I'm told that because of my age now it's unnecessary to be vaccinated.

Polio has not been eradicated from the earth, and we will not see that in our lifetime. Polio survivors are in the 1/2 of 1% of the people who contracted polio and got sick. It is estimated that 35,000 people were paralyzed in 1954 before the vaccine.

4. I'm worried about getting polio again from the vaccine or having side effects from it.

There are no side effects to the polio vaccine. You cannot get vaccine-related polio from the vaccine used **today**. The vaccine is readily available from a Pediatrician.

As long as one person enters the US (or Canada) carrying the virus or just immunized with the Sabin vaccine, that person has the potential to start an epidemic with people who have never been fully immunized against polio!

## Summary of Anesthesia Issues for the Post-Polio Patient

Post Polio Resource Group of Central Florida ©PA Polio Survivors Network Est. 2014; Excerpt From Facebook, Aug 28, 2022

Polio Survivors with Post-Polio Sequelae (PPS) often have all or some of the following symptoms:

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

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

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

### **Do you have an interesting story to tell?**

*Or do you know any good jokes, inspirational or humorous quotes or poems? Then you are invited to email them to:*

[postpolionetwork@gmail.com](mailto:postpolionetwork@gmail.com) or mail them to:

Post-Polio Network (Manitoba) Inc.  
C/O SMD Self-Help Clearinghouse  
825 Sherbrook Winnipeg, MB, R3A  
1M5

## Excerpts: New York adult diagnosed with polio, first US case in nearly a decade

By Brenda Goodman, CNN Updated 4:14 PM ET, Thu July 21, 2022

A person from Rockland County, New York, has been diagnosed with polio, the first case identified in the United States in nearly a decade. The unvaccinated young adult began experiencing weakness and paralysis about a month ago, county Health Commissioner Dr. Patricia Schnabel Ruppert said Thursday. The case comes nearly a month after the UK Health Security Agency warned that it had detected poliovirus in its surveillance of London sewage samples, indicating that there had been some spread between closely linked individuals in North and East London, although no cases had been identified there. This is the first polio case diagnosed in the United States since 2013, according to the [New York Department of Health](#). State and county health officials are advising health-care providers to stay vigilant for additional cases, and they are advising county residents to get vaccinated for polio. The New York case was identified as a revertant polio Sabin type 2 virus, indicating that it was derived from someone who received the oral polio vaccine, which contains a live but weakened form of the polio virus. Officials say this suggests that the virus originated outside the US, where the oral vaccine is still administered, but they are investigating the origins of this particular case.

The **oral polio vaccine** is no longer authorized for use in this country. In the US, only the inactivated polio vaccine has been given since 2000. A person cannot get polio from the vaccine itself, but in recent years, cases of polio linked to shedding from the oral vaccine have arisen in communities that have low vaccination rates. Health officials think the strain of virus the individual contracted originated this way. "Based on what we know about this case, and polio in general, the Department of Health strongly recommends that unvaccinated individuals get vaccinated or boosted with the FDA-approved IPV polio vaccine as soon as possible," State Health Commissioner Mary T. Bassett said in a [statement](#) Thursday. "The polio vaccine is safe and effective, protecting against this potentially debilitating disease, and it has been part of the backbone of required, routine childhood immunizations recommended by health officials and public health agencies nationwide."

# Bruno Bytes First Quarter 2022

EBits and Tidbits from the Post-Polio Coffee house; From Dr. Richard L. Bruno, HD, PhD

**1st Quarter 2022 Topics Include:** Anesthesia, Dopamine, EMG, Joint Damage, Ketamine Infusions, Scoliosis and a study involving PPS and Gray Matter Atrophy

## **On the topic of Anesthesia and Shivering**

Question: I had a procedure to replace a heart valve. I warned them ahead of time about polio survivors needing to be careful and showed my Anesthesia Warning Card. When in the operating room they started something intravenously. I began trembling violently, before they gave me something else to put me out. While recovering later that day, I was in a lot of pain and started trembling violently again.

Dr. Bruno's Response: "Trembling" (shivering) is one of the most commonly recognized problems associated with anesthesia. Shivering doesn't mean that any drug you were given is off limits for polio survivors. The drugs are standard for your surgery and for many procedures requiring anesthesia. If you are concerned about shivering before or after surgery, talk to the surgeon and anesthesiologist and ask for pre-op and post-op warming with a "Bair Hugger" to get warm and stay warm. [https://www.bairhugger.com/3M/en\\_US/bair-hugger-us/](https://www.bairhugger.com/3M/en_US/bair-hugger-us/)

## **On the topic of Dopamine and Polio**

Question: I found the brain stem and hippocampus could have been affected by polio. This is where dopamine is produced. Research shows people with polio are 40% more likely to be schizophrenic because of lower levels of dopamine. Lack of dopamine is probably what causes schizophrenia.

Dr. Bruno's Response: The question misquotes Nielsen's 2007 Danish database study of polio survivors. The study does not say that, "Research shows people with polio are 40% more likely to be schizophrenic because of lower levels of dopamine." Nielsen didn't mention schizophrenia or dopamine, but stated, "Overall, history of poliomyelitis was associated with a 40% increased risk of being hospitalized for a psychiatric disorder. The overall increased risk of psychiatric hospitalizations *could not* be confined to specific groups of psychiatric disorders. Rather, there seemed to be slightly increased risks of several different disorders, especially *milder* psychiatric disorders. These included personality disorders, substance/alcohol abuse, and other *non-psychotic* mental disorders," not schizophrenia. (Note: the Italics are mine.) Nielsen continued: "The reason for the higher odds of having mental problems isn't really known, but it might related to the very painful and fearful experience of contracting polio, the stringent isolation from family for several weeks, and the difficulties of then overcoming physical handicaps and social prejudice," not low levels of dopamine. (reuters.com/article/us-polio-psychiatric-ills/polio-victims-may-suffer-psychiatric-ills-later-idUSKIM67022820070206) There is a 1997 paper by Eagles suggesting a potential relationship between polio and schizophrenia, which is a hypothesis based on coincidences, not research.) Actually, a decrease in dopamine should REDUCE, not increase, the incidence of schizophrenia. In fact, schizophrenia is treated with antipsychotic medications that block the action of dopamine in the brain. ([www.netdoctor.co.uk/medicines/brain-nervous-system/a7483/risperdal-risperidone/](http://www.netdoctor.co.uk/medicines/brain-nervous-system/a7483/risperdal-risperidone/)).

Both David Bodian's research from the 1940's and our studies found polio survivors showing evidence of a decrease in brain dopamine due to poliovirus damage to the basal ganglia that produce dopamine, not the brainstem and hippocampus, which do not. [www.papolionetwork.org/brunoarticles](http://www.papolionetwork.org/brunoarticles)

## **On the topic of EMG and PPS Diagnosis:**

Original Post: I understand an EMG is a test used to eliminate other potential problems like ALS. However, according to two physiatrists here, I do not have PPS based on my EMG results. My left leg has shrunk and I've developed scoliosis. I was told my last EMG showed old polio damage. I had non-paralytic polio as a child. I have suffered with worsening PPS symptoms since the late 90s. No one has an answer for my leg weakness and atrophy while developing scoliosis. I know I need a brace on my left ankle but who do I go to now?

Dr. Bruno's Response: If everything else is ruled out and you have a history of non-paralytic polio, your EMG shows "old polio" (neuron damage), and you have PPS symptoms, you should be treated as having PPS. Since the late 1970s, an office EMG has never been shown to be able to diagnose PPS. You need to see a physiatrist who knows about PPS or is willing to learn.

### **On the topic of EMG and Previous Polio:**

Question: I have a friend, in her 70's who is now developing weakness in her hips. She was around me when I got polio and her cousin was the carrier. The question is can she have a normal EMG and still have had polio? The doctor told her that she could not have had polio because she had a "normal" EMG.

Dr. Bruno's Response: Studies have shown that 10% to 25% of polio survivors have *normal* EMGs because their nerves were damaged but not killed. As a result, there are no neuron "sprouts" to show up on EMG. In one study, almost 10% of patients who had a history of polio muscle weakness, and who were reporting new pain, fatigue or weakness today, had normal EMGs, meaning that there was no EMG evidence that they ever had had polio. Another EMG study found that almost 25% of *paralytic* polio survivors' limbs had no evidence of motor neurons having been killed. Those limbs were classified as having "no clinical polio". However, neurologist Carlos Luciano, using a special "macro" EMG technique, found over-sprouted motor neurons in 85% of muscles that were thought to have had "no clinical polio." This is not surprising since research by David Bodian and Alan McComas showed that seemingly unaffected muscles had lost 40% of their motor neurons to polio. As for being around you when you had polio and her cousin being the carrier, in 5% to 20% of households where poliovirus attacked one family member, another was also stricken. From 1909 to 1955 more than 2000 family members in more than 1000 households were surveyed in which at least one person had polio. On average if one child in a household became ill he "shared" polio with one other sibling of similar age. Just over half of those who became ill were paralyzed, while the others had flu-like symptoms ranging from a fever, sore throat and nausea to a stiff neck and muscle pain. This "minor illness" was caused by the poliovirus but may never have been diagnosed as polio at all, or may have been called "abortive" or "non-paralytic" polio. In three-quarters of the households the first case of polio was paralytic and the second was "non-paralytic."

Bottom line: There's about a 1-in-5 chance that if you had paralytic polio one of your brothers or sisters had non-paralytic polio and may not even have known it. There is more information on EMG and "Non-Paralytic Polio" in the Encyclopedia of Polio and PPS. You will find numerous articles under the topic of "Poliovirus" in the Articles section.

### **On the topic of Joint Damage**

Question: I'm scheduled for a total replacement of my left shoulder. Previous I had my left knee replaced in 2007. I'm also having problems with my major joints on my right side. Can this be from Post-Polio Syndrome?

Dr. Bruno's Response: Joint damage and arthritis are "secondary" PPS, the result of the original "primary": polio virus damage that caused long lasting muscle weakness.

### **On the topic of Ketamine Infusions for Pain**

Question: I'm trying to find information on Ketamine infusion to treat pain for polio survivors.

Dr. Bruno's Response: There's no data on treatment of pain or depression with ketamine in polio survivors yet. My concern is that ketamine is an anesthetic. Therefore, the "normal" dose would be too much for polio survivors and put them out for much longer than non-polio survivors. The usual dose lasts about 2 hours and there are risks: unconsciousness, high blood pressure, dangerously slowed breathing, stomach pain, depression and poor memory. I'd stick to treating the cause of the pain.

Resources:

1. [www.webmd.com/depression/features/what-does-ketamine-do-your-brain](http://www.webmd.com/depression/features/what-does-ketamine-do-your-brain)
2. [www.practicalpainmanagement.com/patient/treatments/medications/ketamine-chronic-pain-management-current-role-future-directions?fbclid=IwAR3yEKO9CoHr3slRAQ7k9VHeEEGOsUCAstOoy7sZkaZet-r-8ZPyNwQgmeE](http://www.practicalpainmanagement.com/patient/treatments/medications/ketamine-chronic-pain-management-current-role-future-directions?fbclid=IwAR3yEKO9CoHr3slRAQ7k9VHeEEGOsUCAstOoy7sZkaZet-r-8ZPyNwQgmeE)

### **On the topic of Pain Sensitivity**

Question: I've NEVER understood this. You say polio survivors are more sensitive to pain than non-polio survivors but have a higher pain tolerance. How is it that I can have a high pain tolerance and be more sensitive? It feels contradictory to me.

Dr. Bruno's Response: It has been known since the 1970s that the body produces its own morphine-like, painkilling opiates called endorphins and enkephalins. The problem for polio survivors is that the poliovirus killed off brain and spinal cord neurons that produce the body's own opiates. So polio survivors can't "medicate" themselves against pain, which is why polio survivors need more pain medication than do non-polio survivors. Our 1984 study showed that polio survivors are TWICE as sensitive to pain as non-polio

survivors, likely due to the lack of endorphins and enkephalins (1) “Normal” levels of pain would be doubled in polio survivors and likely intolerable if polio survivors hadn't developed a higher pain tolerance. Here's another example of sensitivity and developed tolerance. Think about many polio survivors' emotional hypersensitivity to childhood hospital smells (e.g., rubbing alcohol, the smell of wet wool from hot packs). As adults, polio survivors had to develop an increased tolerance to these emotional triggers or they never would have allowed themselves to enter a hospital again. Sadly, many polio survivors have indeed refused to get medical treatment because they didn't develop an increased tolerance for hospitals and medical facilities. (2)

References: (1) Bruno RL, et al. Motor and sensory functioning with changing ambient temperature in post-polio subjects. *Late Effects of Poliomyelitis*. Miami: Symposia Foundation, 1985.

(2) Bruno RL, Frick NM. The psychology of polio as prelude to Post-Polio Sequelae: Behavior Modification and Psychotherapy. *Orthopedics*, 1991;14 (11):1185-1193.

For more information, please read these two articles under the topic of “Psychology” in the Encyclopedia of Polio and PPS: Trauma and Illness as Precipitants of Post-Polio Sequelae and Psychology of Polio as Prelude to Post-Polio Sequelae

### **On the Topic of PPS and Seizures**

Question: I have been experiencing seizure, the kind that puts me in an ambulance. Is this Polio related?

Dr. Bruno's Response: Seizures are not PPS symptoms. There is one very small Turkish study finding 11 of 91 polio survivors had epilepsy. But epilepsy onset was at 17 years old, not in mid-life as with PPS. Seizures should be treated in polio survivors as in on-polio survivors, with doctors being aware that any-seizure drugs may cause increased fatigue in polio survivors. [www.webmd.com/epilepsy/medications-treat-seizures](http://www.webmd.com/epilepsy/medications-treat-seizures).

### **On the topic of PPS Spinal Cord Atrophy**

Question: A February 2022 study claims that patients diagnosed with PPS have spinal cord “gray matter atrophy” in their necks and also have muscle weakness in their arms, hands and feet. Is spinal cord atrophy the cause of PPS?

Dr. Bruno's Response: I read the study when it was published last month and didn't think it was worth mentioning. Only 20 polio survivors said to have PPS were studied and compared to non-polio survivors, not to polio survivors without PPS. It's no surprise that survivors were found to have spinal cord gray matter atrophy that is damage to the “gray” spinal cord motor neurons “polio” means gray in Greek.

This study of only 20 polio survivors links gray matter atrophy not only to post-polio muscle weakness, but also statistically performs multiple comparisons between gray matter atrophy and other factors, e.g., fatigue, pain, depression, age, sex, age at or time since polio. Unfortunately, the statistics applied to draw these conclusions are incorrect, the authors themselves stating, "Given the exploratory nature of these...analyses in this rare disease, we report [statistics] explicitly not adjusted for multiple comparisons." More than 175 subjects would have been required for a valid statistical analysis and appropriate conclusions. The editors of the journal who published the study of "this rare disease" (having 20 million survivors worldwide) should have required appropriate statistics or rejected the paper outright.

### **On the topic of Scoliosis and PPS**

Question: I am 76 yrs old and had polio at 3. I never had scoliosis but over a period of a few years I now have some scoliosis. Is this common in those of us with PPS ?

Dr. Bruno's Response: Scoliosis results from polio-caused muscle weakness that allows back muscles that were less affected to pull the spine toward their side, causing a curve. One estimate from the epidemic years was that 1/3 of young polio survivors developed scoliosis, which resulted in many spinal fusions. Scoliosis can also result from polio survivors' back muscles becoming weaker over time. So, scoliosis is an "indirect" result of PPS.

The Encyclopedia of Polio and Post-Polio Sequelae contains all of Dr. Richard Bruno's articles, monographs, commentaries, “Bruno Bytes”. The Encyclopedia of Polio and PPS is also available by a direct link from: [www.postpolioinfo.com](http://www.postpolioinfo.com)

# Membership Application Form



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\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Date*

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