



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

April 2018

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

April is Polio Awareness Month in Pennsylvania.

When we think “Polio Awareness” we must think beyond our own back door and realize this isn’t just a local or even a national issue. A critical “Polio Truth” is that the reality of the effects of this terrible disease is a global issue.

Both [Richard L. Bruno, HD., PhD.](#) and [William M. DeMayo, MD.](#) have given us articles this month that speak to all of us – regardless of where we call home. Both of these outstanding professionals reflect in their writing the hope that we will all learn to *thrive* in spite of what this disease did to us.

There has been lots of conversation in the Post-Polio Coffee House about Dr. Bruno’s *Ten Commandments of PPS*. He has updated those wonderful guidelines for us to share.

Dr. DeMayo is in Abu Dhabi, having taken on the unique opportunity with Capital Health as the Director of Physical Medicine and Rehabilitation, developing their first inpatient rehabilitation hospital. As a result of this experience, he has started a series of articles for us titled *Lessons from Abroad*. His series begins with information about a country very few of us are familiar with.

As we travel around the Keystone State, doing presentations at Senior Expos, Immunization Coalition Meetings and Rotary Clubs there are two common themes and reoccurring questions:

- “Hasn’t Polio been eradicated?”
- “Why do we need to vaccinate our children? It’s over.”
- “Post-Polio Syndrome? What’s that?”

The answer to these questions is “No, it’s not over” and “Post-Polio Syndrome is real”.

With enormous gratitude to the Global Polio Eradication Initiative, the world is so close to any new cases of Polio coming to an end, but sadly they have yet to be successful in being able to declare Afghanistan, Pakistan or Nigeria “Polio Free”, classifying them as Endemic countries. (They separate the Polio threat by [Endemic](#), [Outbreak](#) and [At Risk](#) Countries). Why is that important to those of us here in the U.S. and in all countries that are free of this disease ? Because another critical Polio Truth is that it is ONLY a plane ride away. Should a yet to be vaccinated child who is carrying the disease, come in contact with an unvaccinated child, it could happen again here in the U.S. and anywhere - more quickly than we can imagine.

According to the World Health Organization, there are an estimated 20 million Polio Survivors in the world. The vast majority of these survivors will develop Post-Polio Syndrome – often becoming more disabled as a result. Once the Global Eradication Initiative is successful (and we believe they *will* be successful), we bring forward another critical Polio Truth. Because of Post-Polio Syndrome, it will take a *full* generation to rid the world of the effects of this disease.

April is the time we open up the conversation once again.

Let’s end this terrible disease once and for all.

With Polio, the number Zero truly matters.

The Global Polio Eradication Initiative has five core partners - the World Health Organization (WHO), Rotary International, the US Centers for Disease Control and Prevention (CDC), the United Nations Children's Fund (UNICEF) and the Bill & Melinda Gates Foundation. Its goal is to eradicate polio worldwide. We believe that this well organized, and seemingly tireless, Polio Eradication initiative has created an amazing infrastructure that if properly preserved, can provide human services to the remote corners of the world for decades to come.

As of April 1, 2018 there were 7 cases of [wild polio](#) in the world. Those of us reading this newsletter understand first hand just how stubborn this virus can be to eradicate.

We're "only" individuals with very limited resources. What can WE do?

We believe that together, we CAN make a difference.

When we started this Network in 2014, we found that Rotary International quickly became one of our most trusted resources for information regarding the current status of Polio in the world. When our team decided to start "making a difference", it seemed like it was a natural fit for us to participate in Rotary International's "End Polio Now" campaign. In 2016 and 2017 we participated in "Purple Pinkie" events. What we were discovering was that although Rotary Clubs all over the world had been tirelessly raising funds to eradicate Polio since 1985, very few Rotarians had ever actually seen first hand, the pain and disability of the disease. Our active participation has brought "home" that reality to the hundreds of participants we have met.

We also realized that with Rotary's Polio Plus initiative, a little bit can make a huge difference. For every dollar raised by Rotary, the Gates Foundation will turn it into \$3. A \$10 donation (turned into \$30 by the Gates Foundation) results in approx. 46 children being able to have the Polio vaccine. (The Rotary Foundation is rated 4 Stars with [Charity Navigator](#), and has been for many, many years). Where else can a \$10 donation make such a difference?

Engaging with Rotary's Mission of *Service Above Self* took us "out of our box" and in 2016 Team Survivor was born. In 2017, we decided to engage even more fully. In addition to developing the idea of Team Survivor we changed our Polio Awareness Month activities to include the Polio Truth of pain and disability in a message that supported the need for vaccination. Rotary International gave us permission to create the "entwined" logo.



Join [Team Survivor 2018](#)

How can you participate? It's easy.

What is Team Survivor? It is quite simply a means for Polio Survivors, our friends and families to come *together* in a thriving, spirited way to help rid the world of this disease we are all so *very* tired of. In just two years, survivors and family members in our network have sent donations providing more than 19,000 Polio vaccinations to children in the most difficult to reach corners of the world. NO donation is too small. That's what makes it so special.

1. Make a check out to [The Rotary Foundation](#) and put "Polio Plus" in the subject line. Mail your check with the form.
 2. Would you like to make your donation online? There are two options:
Option #1 - Go to the END POLIO NOW Page on our website:
<https://www.papolionetwork.org/end-polio-now-rotary-international.html>
"Click" on Donate. In the section that refers to "Special Instructions to the Seller", please Enter: Rotary Foundation – Polio Plus (If you are donating in the name of a survivor, please enter it). We will send you a confirmation of the donation going to Polio Plus in **your** name.
Option #2 - Go to [ROTARY'S](#) "End Polio Now" Website : <https://www.endpolio.org/donate>
Please forward your payment confirmation to us: info@polionetwork.org
 3. Have you already made a 2018 donation to Rotary's Polio Plus? Just email us the confirmation.
 4. Are you a Rotarian? Please include your District and ID# for your Paul Harris Fellow credit.
- Everyone who makes a donation this way will receive a confirmation of thanks from Team Survivor.

Together we can make a difference.

Without question, the one thing we ALL share is the prayer that with world wide vaccination; death and disability from the Polio Virus will soon be gone . . . **Forever.**



THE TEN COMMANDMENTS OF PPS

Richard L. Bruno, HD., PhD.

Director, International Centre For Polio Education

(Rev. 2018)

After 35 years of searching, archaeologists from The Post-Polio Institute have unearthed the "Commandments" for treating Post-Polio Sequelae (PPS) . . .

1) Listen to Yourself!

Polio survivors often turned themselves off from the neck down after having polio. The first step in treating PPS is to listen to yourself, to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms. However, polio survivors sometimes listen too much, to vitamin salesmen saying some herb or spice will "cure" PPS, to other polio survivors who warn that you will eventually have every possible PPS symptom and to friends and family members (and the voices in their own heads) saying you're lazy and that you must "use it or lose it." Polio survivors need to listen to their *own* bodies, not to busybodies.

2) Activity is Not Exercise!

Polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs that their muscle weakness will go away. The opposite is true: the more you overuse your muscles the more strength you lose. Muscles affected by the poliovirus lost at least 60% of their motor neurons; even limbs you thought were not affected by polio lost about 40%. Most disturbing is that *untreated* polio survivors with new muscle weakness lose on average 7% of their remaining, poliovirus-damaged motor neurons per year, while survivors with severe weakness can lose up to 50% per year! You need to substitute a "conserve it to preserve it" lifestyle for the "use it or lose it" philosophy. Polio survivors need to work smarter, not harder.

3) Brake, Don't Break.

The follow-up study of our patients showed that taking two 15 minutes rest breaks per day - that's doing absolutely nothing for 15 minutes - was the single most effective treatment for PPS symptoms. Another study showed that polio survivors who paced activity -- that is worked and then rested for an equal amount of time -- could do 240% *more* work than if they pushed straight through. Our patients who took rest breaks, paced activities and conserved energy had up to 22% less pain, weakness and fatigue. But polio survivors who quit or refused therapy had 21% *more* fatigue and 76% *more* weakness. For polio survivors, slow and steady wins the race.

4) A Crutch is Not a Crutch . . .

. . . and a brace is not a sign of failure or of "giving up." You use three times less energy (and look better walking) using a short leg brace on a weakened leg. Overworked muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches (dare I say a wheelchair or a scooter) if they decrease your symptoms and make it possible to finally take that trip to Disney World? I know, you'll slow down and take care of yourself "when you're ready" and use a wheelchair "when there's no other choice." You don't drive your car until it stops because it's out of gas. Why drive your body until it's out of neurons?

5) Just Say "No" to drugs, unless...

More than a half dozen studies have failed to find any drug that treats PPS. And there have been no studies showing that herbal remedies, electric stimulation or magnets reduce symptoms. Polio survivors shouldn't think that they can run themselves ragged, apply a magnet or pop a pill and their PPS will disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done! Masking symptoms -- with magnets or morphine -- will not cure PPS. However, two of our studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury (see #10 on the next page).

6) Sleep Right All Night. A significant majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders, such sleep apnea (not breathing), hypopneas (shallow breathing) or muscles twitching and jumping all over your body during the night. However, polio survivors are

usually not aware that they stop breathing or twitch. You need a sleep study at a sleep disorders center if you awaken at night with your heart pounding, anxiety, shortness of breath, choking, twitching or awaken in the morning with a headache or not feeling rested. "Post-polio fatigue" may be due to a *treatable* sleep disorder.

7) Some Polio Survivors Like it Hot. Polio survivors have cold and purple "polio feet" because the nerves that control the size of blood vessels were killed by the poliovirus. Polio survivors' nerves and muscles function as if it's 20 degrees *colder* than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of the silk-like plastic fiber polypropylene that holds in your body heat.

8) Breakfast Is the Most Important Meal of the Day.

For once Mom was right. Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. Our dietary study showed that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When our patients follow a hypoglycemia diet (have 16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your mid-day yawning.

9) Do Unto Yourself as You Have Been Doing For Others.

Many polio survivors were verbally abused, slapped and even beaten by therapists or family members when they had polio to "motivate" them to get up and walk. So polio survivors took control, becoming Type A super achievers, "the best and the brightest," doing everything for everyone...except themselves. Many polio survivors do for others and don't ask for help because they are afraid of being abused again if they even look "disabled." Isn't it time that you got something back for all you've done for others? Accepting assistance is not the same as being dependent. Accepting assistance can actually keep you independent. But appearing disabled by not doing for others, asking for help or using a scooter, will be frightening. So please remember: If you don't feel guilty or anxious you are not taking care of yourself and managing your PPS.

10) Make Doctors Cooperate Before They Operate. Polio survivors are easily anesthetized because the part of the brain that keeps them awake was damaged by the poliovirus. Polio survivors also stay anesthetized longer and can have breathing trouble with anesthesia. Even nerve blocks using local anesthetics can cause problems. All polio survivors should have lung function tests before having a general anesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist - and especially your anesthesiologist - long before you go under the knife. Polio survivors should NEVER agree to having same-day surgery or outpatient tests (even an endoscopy) that require an anesthetic without their doctor 1) Reading the information on polio survivors increased sensitivity to anesthesia and 2) Being prepared to admit them overnight if too much anesthesia is given and the polio survivor is unsafe to leave the hospital.

The Golden Rule for Polio Survivors.

If anything causes fatigue, weakness, or pain, DON'T DO IT (or do a lot *less* of it) !

The Golden Rule for Polio Survivors' Friends & Family.

See no evil, hear no evil . . . and help only when asked.

Polio survivors have spent their lives trying to look and act "normal." Using a brace they discarded 30 years ago and reducing their super-active lifestyle is both frightening and difficult to do. So, friends and family need to be supportive of life-style changes and accept survivors' physical limitations and new assistive devices. Most important, friends and family need to be willing to do the physical tasks a polio survivor should not do...but only when the polio survivor asks. Friends and family need to know everything about PPS but say nothing: neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of themselves and ask for help when they need it.

[DR. BRUNO'S](#) PPS Library and a direct "link" to Bruno Bytes can be found [HERE](#).

Lessons from Abroad

[William M. DeMayo, MD.](#)

As most readers already know, this fall I took a position working in Abu Dhabi, which is part of the United Arab Emirates (UAE). I accepted a unique opportunity with Capital Health, as the Director of Physical Medicine and Rehabilitation, developing their first inpatient rehabilitation hospital. This Specialized Rehabilitation Hospital (www.ch-srh.ae) will be a model of care for the United Arab Emirates and the Gulf region. As such, my posts to this network have been few in the past 6 months. I thought I would start up again by sharing some of the many new perspectives that I have gained.

After 30 years of practicing Physical Medicine & Rehabilitation in the United States, I am astounded at the new insights I am having by simply looking at life and patient related issues from a different angle. I hope that these perspectives are not only interesting but also help Polio survivors and caregivers take a step back in their own situations to gain new perspective. It is a simple fact of the human condition that we get used to approaching problems, concerns and difficulties from a consistent point of view – that can be good sometimes and other times it can restrict our thinking. Spirituality has always been important to address in my work with patients. This is what allows us to “step out of ourselves” and break restrictive thoughts and emotions.

The culture and health care in the UAE is clearly very different and will provide many potential challenges to our thinking. At the same time, I have also been struck by how human nature is human nature. The saying “We are all the same and we are all different,” is true on many levels. It is my hope that as you read this and the articles I plan to write in the next few months, you will try to not focus on the fact that the UAE is half way around the world but rather let it become part of *your* world which you have not yet explored – like a previously unopened box in the attic with family treasures that take us to a different place of thinking.

Certainly, what I have learned in 5 months can't be condensed into one article so I will provide an outline of sorts for future articles and modify as we go along. I must start by admitting that I had NO IDEA about the United Arab Emirates (UAE) prior to my investigations over last summer so no one should feel embarrassed by not knowing where it is on the map. Secondly, I think it is important to share some of the cultural issues here since they will impact much of what I discuss.

These are the subjects I would like to write about as we move forward into the next few months.

1. Overview of Abu Dhabi, United Arab Emirates (UAE)
2. Cultural issues and dramatic growth in the UAE and how they impact health care
3. Current status of health care and Rehabilitation Medicine in the UAE.
4. Accessibility issues and services for “People of Determination” in the UAE.
5. Rehabilitation Vision – moving forward in helping the UAE develop world class services.



Lessons from Abroad (Part 1)

An Overview of the Abu Dhabi, United Arab Emirates (UAE)

[William M. DeMayo, MD.](#)

- The United Arab Emirates (UAE) is a federal monarchy on the Persian Gulf with Oman to the East and Saudi Arabia to the South. Marine borders include Qatar to the west and Iran to the North.
- Abu Dhabi is the capital of the UAE which is the most westernized of the Arabic countries.

- Second most populated city in the UAE, after Dubai (1.5 hr. drive away).
- Population (Only 20% are citizens).
 - UAE Nationals - 0.5 Million
 - Non-Nationals - 2.25 Million

- There are more than 2,000 parks and 10 km of public beaches here.
- The Louvre Abu Dhabi opened in 2017 and the Guggenheim is pending.
- Inexpensive bike share stations are throughout the city.
- Four of the top ten Seven star hotels are in Abu Dhabi or in nearby Dubai.
- Popular outdoor activities include beach sports, boating, biking, camping and desert activities
- Abu Dhabi is extremely safe, even late at night.
 - 1) Non-nationals that commit crimes are deported, unemployment is extremely low, and drug laws are very strict.
 - 2) Claims to the [safest city on the planet](#).
- Taxis are everywhere and extremely inexpensive - a 2 mile cab ride will cost about \$3.
- The local currency (the Dirham) is tied directly to the US dollar so there is no concern about fluctuating exchange rates.
- NYU Abu Dhabi - almost 40 Acres and can accommodate 2,600 students.
- Cleveland Clinic Abu Dhabi is an amazing 364 bed facility and has centers of excellence in Heart/Vascular, Neuro, GI, Eye, and Respiratory/Critical Care. (They do not have inpatient rehabilitation).

• Language

Arabic is the official language but English is the business language and almost everyone speaks at least some English. Most signage is in both languages (they even have Hardees, Dunkin Donuts and Applebees)!

• Religion

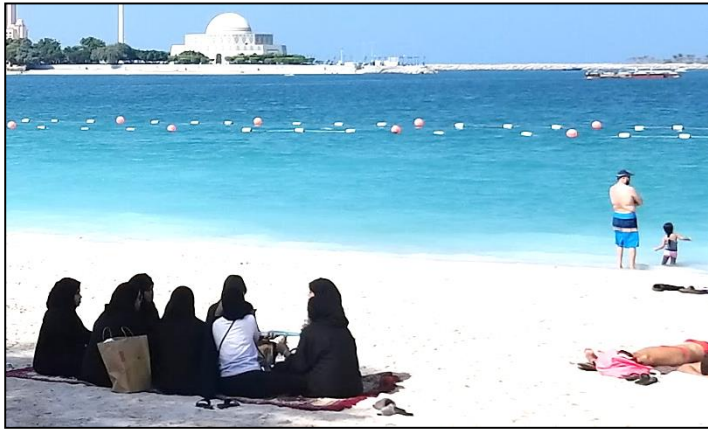
- 1) The UAE is clearly an Islamic country that respects people of all faiths.
- 2) The government in Abu Dhabi has spent millions in constructing and renovating churches.

• Alcohol

- 1) Laws generally allow expatriates to drink but protect local heritage.
- 2) Expatriates may apply for a license to purchase and consume alcohol.
- 3) UAE national citizens and individuals identified as Muslim on their passport are not eligible for this license.
- 4) Drinking and driving laws are very strict as are laws for drug abuse with a zero tolerance enforcement so people take a taxi after one glass of wine.



- The cost of living in Abu Dhabi is surprisingly low.
 - 1) Rent tends to be high but many other costs are very low including any service related cost.
 - 2) Overall, the cost of living is 35 % lower than New York City.
- Dress
 - 1) Emirate citizens wear traditional dress.
 - 2) Many expatriates (those living in Abu Dhabi who are from other countries) wear dress from their home country.
 - 3) U.S. expatriates will generally not dress differently than they would at home when in most areas of the city including the beaches.
 - 4) Beach attire or very revealing clothes outside the beach area will be frowned upon.
 - 5) Out of respect for the local population when at the malls, the shoulders should be covered and short shorts avoided.
 - 6) Government buildings and Mosques have strict dress codes, which those of us who are non-residents must honor.



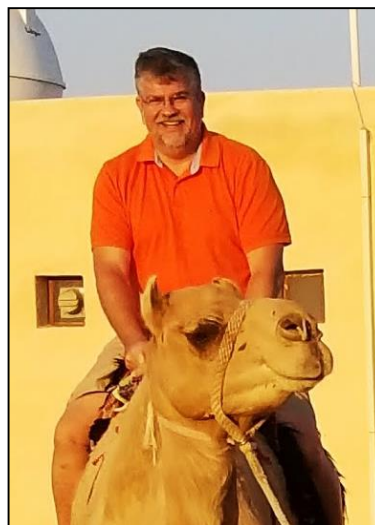
I took this photo at the beach – it's easy to see who the Abu Dhabi nationals are.



When we visited the Grand Mosque, my wife dressed as required for women – arms, legs and head covered. Men have it easier !



Abu Dhabi is a clean and very modern city, right on the Persian Gulf.



I thought **I** was going to need a Rehabilitation Physician after spending an afternoon on a camel !

A Link to his talk at our Conference and all of Dr. DeMayo's articles are available in PDF format, on our website.

polionetwork.org/demayo

Anesthesia Warning Cards and Documentation re: Polio Survivor's Increased Sensitivity to Anesthesia

is easily available on the Anesthesia Warning Page of our [Website](http://www.polionetwork.org/anesthesia-card) – [polionetwork.org/anesthesia-card](http://www.polionetwork.org/anesthesia-card)

This card has a “scan” code that links directly to the articles written by:

Dr. John Bach, MD.

Dr. Richard L. Bruno, HD., PhD.

and Dr. Selma Calmes, MD.


This updated version is easy for your physician to access this information. They simply hold their phone up to the scan code on the card. Then, they can read the four articles (written by the professionals above) and of equal importance, they can read their biographies.

Thank you Dr. William DeMayo, MD. for lending his professional expertise in the development of this updated card.

ANESTHESIA WARNING!

I am a **Polio Survivor**

- 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



I am a **Polio Survivor with Post-Polio Sequelae**

Name: _____

I have these Symptoms (checked):

<input type="checkbox"/> Overwhelming Fatigue	<input type="checkbox"/> Muscle Weakness
<input type="checkbox"/> Muscle and Joint Pain	<input type="checkbox"/> Sleep Disorders
<input type="checkbox"/> Cold Intolerance	<input type="checkbox"/> Difficulty Swallowing
<input type="checkbox"/> Difficulty Breathing	<input type="checkbox"/> Sensitivity to Anesthesia

(Scan Code for Anesthesia Information - Over)
www.polionetwork.org/anesthesia-card

Polio

It's only a plane ride away.

Please Have Your Children Vaccinated.



The Pain and Disability from Polio Lasts a Lifetime.



Check out the outstanding video – Why Zero Matters.

It explains just how it's possible for Polio to be so far away . . . and yet so close.

**Are you Looking for Information?
Check out the new “Search Bar” on our website.**

It is located at various locations on our website.
Enter the Topic or Author and see what you can find.

**We are truly grateful for your kind words of support.
Your generous donations will help our work continue.**

With their permission,
we have noted our generous contributors on our website.
polionetwork.org/#donate-contact



April

Spring

Do you have a topic you would like us to cover? Please let us know.
Always feel free to contact us.

[The Polio Network Team](#)

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THANKS.



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