PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

July 2018

Our Mission:

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

Summer is Here

Polio has always been a disease that is especially active during the carefree days of summer. For polio survivors and our families, this time of year offers great contrast. It is often a time of reflection and the resurgence of memories of pain and isolation. On the other extreme, as survivors, the warmth of the summer months brings marvelous relief as muscles relax and so many of the "cold weather" symptoms of PPS take a much needed vacation.

Along those lines, we welcome the third part of his wonderful series "Lessons from Abroad". William M. DeMayo, MD is experiencing a different kind of summer on the other side of the world. Summers in Abu Dhabi (the UAE) bring regular temperatures in the three digits. As he said recently, "Let's put it his way... I think I could sell windshield wipers for eyeglasses since they completely fog up with condensation the second you leave the car's air conditioning". Thank you Dr. DeMayo for taking us along on your amazing journey abroad.

Richard L. Bruno, HD, PhD. helps us understand the impact of the summer disease that caught us all by surprise. Often referred to as the Summer Grippe, "Non-paralytic" Polio has affected many survivors more than was previously understood.

There's only one way to realize the final end of the pain and disability of this summertime disease. As the Global Polio Eradication Initiative (GPEI) fights this long, difficult battle, Polio seems to be in the news on a regular basis these days. Do you have a clear understanding of abbreviations like "OPV", "VDP" and "IPV" ? Don't worry, you're not alone. This month, we are starting a series explaining these terms and how they apply to the eradication of the disease we are all so weary of.

It may be summer, but Nicole Thornton, MSPH and Priya Duggal, PhD, MPH from the Johns Hopkins Bloomberg School of Public Health are working hard and have asked for your help. We often get asked to contact you to participate in studies. Unless we can verify the quality of the study, we always turn down the opportunity. This time, we're thrilled to be able to participate. All the information is on page 5 of this newsletter, and in the "What's New" section of our website.



Bruno Bytes

Richard L. Bruno, H.D, PhD
Chairperson, International Centre for Polio Education

On the topic of How Muscles were affected by Polio

Question: How Many Muscles were Affected by the Polio Virus ?

Dr. Bruno's Response: If the poliovirus got into your spinal cord, some motor neurons going to every muscle were damaged or killed. This was known in the 1940s and comes from David Bodian's research on monkeys and humans infected with polio. He found that 96% of motor neurons were damaged by the poliovirus but that at least 60% had to be killed before muscles show any weakness. So "unaffected limbs" and "non-paralytic" polio survivors could have lost 59% of their motor neurons and not have known!

This is why you can't "pump up" up your "good" leg or arm through exercise to compensate for muscle weakness on the other side of your body. It's also why polio survivors so often come in confused, reporting that their "good leg" is getting weaker even though they "didn't have polio" in that leg. The poliovirus went everywhere!

On the topic of a "Mild" case of Polio

Question: How Many Polio Survivors ARE there? My sister had paralytic polio and I had what the doctor said was the flu at the same time. Could my "flu" have been a mild case of polio?

Answer: If the poliovirus entered the nervous system there was no mild "case." The poliovirus killed brain stem (bulbar) neurons even if it didn't affect the spinal cord. And you had to have 60% of your spinal cord motor neurons killed to have any lasting paralysis!

With regards to having have had a "mild case," here's another stat. We went through the Mayo Clinic's Olmsted county data base. We found data that indicates there are 150,000 Americans who had polio (usually siblings of paralytic polio survivors) who were never diagnosed, not even as having "non-paralytic" polio or the "summer grippe."

Bottom lines:

1) Poliovirus did lots of damage whether or not you had muscle weakness or paralysis.
2) We have no idea how many people had polio.

Can a "mild" case (Non-Paralytic Polio) cause PPS?

Dr. Bruno's Response: This study published in the American Journal of Physical Rehabilitative Medicine explains it.

Paralytic vs. "nonparalytic" polio: distinction without a difference?

Am J Phys Med Rehabil. 2000 Jan-Feb;79(1):4-12. Bruno, RL PhD.

Abstract: Nonparalytic polio (NPP) is commonly thought to be synonymous with "abortive polio," in which the poliovirus neither entered the central nervous system nor damaged neurons. Described are two epidemic illness-"The Summer Grippe" and Iceland disease-apparently caused by a low virulence but neuropathic type 2 poliovirus. Studies show that neuronal lesions in the brain and spinal cord and muscle weakness were common in NPP, and epidemiologic studies document late-onset weakness and fatigue in 14% to 42% of NPP survivors. These findings indicate that clinicians should not require a history of paralytic polio, electromyographic evidence of denervation, and new muscle weakness for the diagnosis of "Post-Polio Syndrome" but should be aware that NPP, and possibly even poliovirus-induced "minor illnesses," can be associated with acute central nervous system damage and late-onset muscle weakness and fatigue.

Dr. Richard Bruno's Q & A's have been accumulated in one place.
Bruno Bytes are available on our website through a direct "link" on Dr. Bruno's Website

Looking for a specific topic? With Dr. Bruno's help, we have created an "Index" by Subject, the most current of which is on that page of the website as well.

Lessons from Abroad, Part 3
The Current Status of Health Care and Rehabilitation Medicine in the UAE

Willliam M. DeMayo, MD.

In this third part of our series on lessons learned during my work in Abu Dhabi, I hope to give a flavor of what Health Care and Rehabilitation is like in the UAE and Gulf Region. There is no question that patients and professionals alike look upon the US as the "gold standard". US physicians have immediate credibility, and the insurance system tries to follow Medicare guidelines and US quality. Key Performance Indicators (KPI's) are implemented whenever possible. While it would be easy to develop an attitude of superiority, I find it important to keep perspective. First, I consider myself a guest in someone else's home, so I don't judge. Secondly, when I was born, this whole country was sand dunes and tents. The skyline of Abu Dhabi and Dubai attest to the incredible changes to infrastructure. Every day I am amazed driving past the Grand Mosque on the way to work, looking at the construction of our new hospital atrium or simply looking off my balcony……

At the same time, healthcare has grown at a breakneck speed. Nonetheless, it is fair to say that it takes longer to build a healthcare system than buildings. Health care literacy is very low among some of the population – especially older Emirates and poorly educated laborers (expatriates from countries like Pakistan and India).

While I can certainly not give a comprehensive review of Health Care or Rehabilitation here, I will try to briefly summarize a few key areas including Physician Services, US hospitals in Abu Dhabi and status of Rehabilitation Medicine here.

- Physician Services/Licensing

In contrast to the US, physicians do not have their own license that can be used anywhere. It is attached to a facility and that facility must agree to transfer the license to another provider. The process of getting a license is long, frustrating and exhausting as one needs to get a host of documents dating back to college and most need to go through an elaborate "attestation" process to prove they are authentic. This process includes local notarization, then a stamp from the State government, then a stamp from the US Department of State and finally approval from the UAE Embassy in Washington. I am told that in years past there was an epidemic of fraud in medicine here and this was the government's solution.

For those of you who think the US is over regulated, you haven't seen anything!

Also, there are 3 very distinct levels of Physicians here. As a result, the quality of care can vary from scary bad to outstanding.

- General Practitioners – This could be a physician from any country, such as Somalia, with a Bachelor's Degree in medicine. They need to pass a written test and can then be licensed but are able to bill only very basic levels of care.
- Specialists – These physicians generally come from more developed countries and need to pass a much more rigorous written and oral test to be licensed at this level. They can see more complicated patients and bill a higher level of care.
- Consultants – These physicians come from countries like the US, UK, Canada and Australia. They need to pass an even more difficult set of written and oral exams. Of note, a US Board Certified physician automatically has testing requirements waved and comes in as a top tier Consultant once they get through the certification and attestation process.

- US hospitals in the UAE
  - Several US hospitals have facilities in the UAE. The best known is certainly Cleveland Clinic Abu Dhabi. This is a large palace of a facility that was built to reduce the need for Emirati citizens to go to the US or Germany for care. If care for a condition is not available in the UAE, then it is the government's policy to pay for an Emirati citizen to go abroad for care. This often involves trips that are weeks or months and includes funding for family members and a spending allowance. The cost savings of keeping that care in country is obviously enormous. This has led to incredible investments including the amazing facility of Cleveland Clinic Abu Dhabi with it's unique structure and enormous atrium complete with full grown palm trees.

  - Other US hospitals have affiliations with local hospitals. For example, the rehabilitation hospital I am working for, Specialized Rehabilitation Hospital, has a 5 year affiliation with Shirley Ryan Ability Lab (formerly called Rehabilitation Institute of Chicago) – the number one ranked rehabilitation facility in the US (arguably in the world). This affiliation goes far beyond name branding and includes ongoing consultation and quality of care monitoring to assure the level of care is as close as possible to that provided in the US.

- Rehabilitation in the UAE
  - In many ways, rehabilitation in the UAE is in it's infancy. Even the term "Rehabilitation" has vague meaning to many providers and is often used for individuals in Long Term Care who have no functional goals. This may include individuals who are non-responsive and on long term ventilator care (ventilators are not discontinued here).
  - Acute Inpatient Rehabilitation Units are just starting to appear. Most are converted

"villas" (residences) that are on the grounds of Long Term Care facilities. Specialized Rehabilitation Hospital will be the first rehabilitation facility built specifically for that purpose in Abu Dhabi.

- High end equipment such as robotic devices and virtual reality exercise equipment is sought out by some Emirati patients even if there is little data to prove its usefulness.
  Providing quality care and outcomes requires doing a careful dance between known/proven treatment methods and meeting expectations for patients and families who may surf the internet but have limited health care literacy.
- Similarly, in outpatient rehabilitation, using equipment such as electrical stimulation, shock wave or ultrasound is expected even if not clearly indicated for a condition. It is often necessary to provide some of these services in order to also get a patient to "buy in" to the need for individualized exercise in therapy and at home.

In summary, working in HealthCare in the UAE is humbling. I have become acutely aware of the quality of care in the US. For all the debates about how to administer Health Care in the US, we should not loose sight that the quality of care provided is the envy of the world. I am also very aware of the fact that patients in the US are far more equipped to be knowledgeable health care consumers. If you began reading this article feeling overwhelmed with Healthcare decisions in the US, it's important to remember that Americans are well ahead of so many others around the world, in our understanding and expectations of quality. I am realizing this truth more each and every day I am here.

You can find the first two articles in this series and all of Dr. DeMayo's informative articles on our website.

JOHNS HOPKINS
BLOOMBERG SCHOOL
of PUBLIC HEALTH

Study To Find Genetic Susceptibility Causing AFM (Acute Flaccid Myelitis)

We are conducting a research study through the Johns Hopkins Schools of Public Health and Medicine involving patients with acute flaccid myelitis (AFM), a polio-like condition for which the cause remains unknown. We theorize that there is an underlying genetic susceptibility that causes the severe reaction we are seeing among a small subset of children exposed to the causative agent (from Aug. 2014 – Jan 2018, 320 cases were reported to the CDC). Due to the similarities to polio, we are expanding our study to include polio survivors.

Briefly, our study is seeking to enroll individuals who had paralysis following infection with poliovirus. We will ask to collect a saliva sample from each patient, which we will extract DNA from. We will also ask them to fill out a survey with a few brief questions related to personal and family medical history. We will then compare their DNA to that of AFM patients to search for genetic variants that both groups share. Please let us know if you have any questions or concerns about the study. Please contact us directly. We look forward to hearing from you.

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The Two Polio Vaccines. What's the Difference?

Inactivated Poliovirus Vaccine (IPV)

Inactivated polio vaccine (IPV) was developed in 1955 by Dr Jonas Salk. Also called the Salk vaccine, IPV consists of inactivated (killed) poliovirus strains of all three poliovirus types. IPV is given by intramuscular or intradermal injection and needs to be administered by a trained health worker. IPV produces antibodies in the blood to all three types of poliovirus. In the event of infection, these antibodies prevent the spread of the virus to the central nervous system and protect against paralysis.

Advantages - As IPV is not a 'live' vaccine, it carries no risk of VAPP. (Vaccine-associated paralytic poliomyelitis (VAPP) is an adverse event following exposure to the oral polio vaccine (OPV). IPV triggers an excellent protective immune response in most people.)

Disadvantages - IPV induces very low levels of immunity in the intestine. As a result, when a person immunized with IPV is infected with wild poliovirus, the virus can still multiply inside the intestines and be shed in the feces, risking continued circulation. IPV is over five times more expensive than OPV. Administering the vaccine requires trained health workers, as well as sterile injection equipment and procedures.

Safety - IPV is one of the safest vaccines in use. No serious systemic adverse reactions have been shown to follow vaccination. It is highly effective in preventing paralytic disease caused by all three types of poliovirus. (It is currently the only Polio vaccine administered in the US.)

Oral poliovirus vaccine (OPV)

The oral polio vaccine (OPV) is simple to administer. A few drops, given multiple times, can protect a child for life. (OPV) are the predominant vaccine(s) used in the fight to eradicate polio. There are different types of OPV, which may contain one, a combination of two, or all three different serotypes of attenuated vaccine. Each has their own advantages and disadvantages over the others.

The attenuated poliovirus(es) contained in OPV are able to replicate effectively in the intestine, but around 10,000 times less able to enter the central nervous system than the wild virus. This enables individuals to mount an immune response against the virus. Virtually all countries which have eradicated polio used OPV to interrupt person to person transmission of the virus.

Advantages - OPVs are all inexpensive (US $0.12-$0.18 for countries procuring through UNICEF in 2016). OPVs are administered orally and do not require health professionals or sterile needle syringes. As such, OPVs are easy to administer in mass vaccination campaigns. OPV is extremely safe and effective.

Disadvantages - For several weeks after vaccination the vaccine virus replicates in the intestine, is excreted and can be spread to others in close contact. This means that in areas with poor hygiene and sanitation, immunization with OPV can result in 'passive' immunization of people who have not been vaccinated.

In extremely rare cases (at a rate of approximately 2 to 4 events per 1 million births [1]) the live attenuated vaccine-virus in OPV can cause paralysis. In some cases, it is believed that this may be triggered by an immunodeficiency. The extremely low risk of vaccine-associated paralytic poliomyelitis (VAPP) is well accepted by most public health programs. Very rarely, when there is insufficient coverage in a community the vaccine-virus may be able to circulate, mutate and, over the course of 12 to 18 months, reacquire neurovirulence. This is known as a circulating vaccine-derived poliovirus.

Recommended Use(s) of the two vaccines.

An increasing number of industrialized, polio-free countries are using IPV as the vaccine of choice. This is because the risk of paralytic polio associated with continued routine use of OPV is deemed greater than the risk of imported wild virus.

However, as IPV does not stop transmission of the virus, OPV is used wherever a polio outbreak needs to be contained, even in countries which rely exclusively on IPV for their routine immunization program. Once polio has been eradicated, use of all OPV will need to be stopped to prevent re-establishment of transmission due to VDPVs.

This information in it's entirety is available here: http://polioeradication.org/

The GPEI has been publishing an outstanding series of videos, that explain these vaccines in language we can all understand.

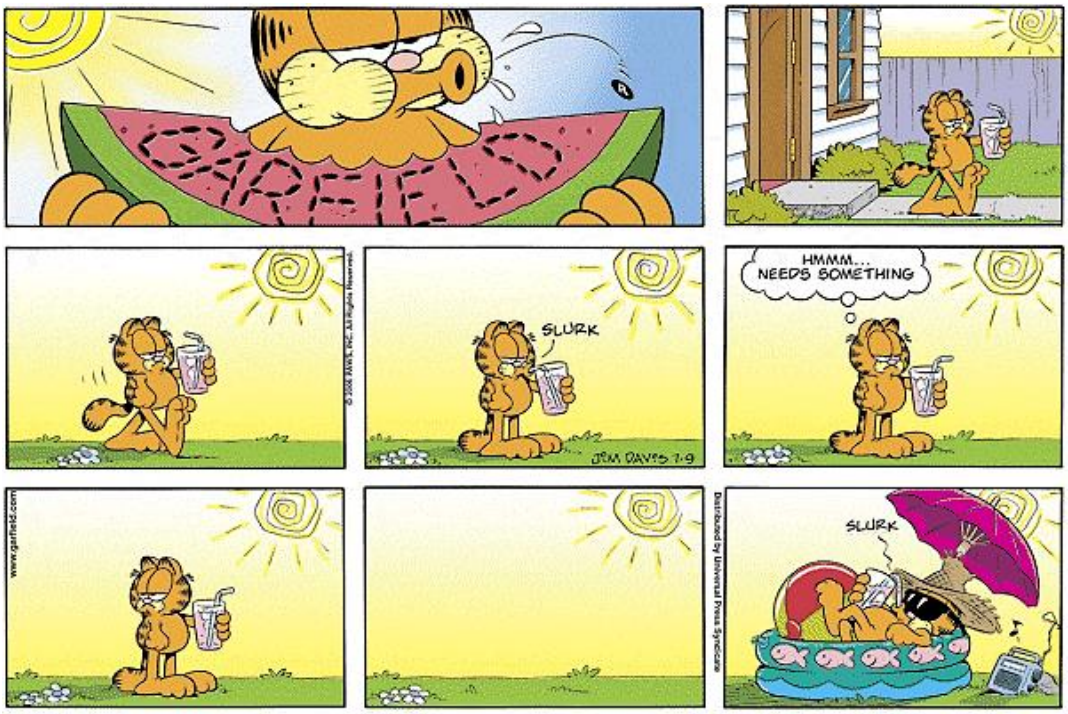
We have put them all into one place on our website, that allows easy viewing.

POLIO

Is a Permanently Disabling and often Deadly Virus that has NO cure.

Because of Post-Polio Syndrome (PPS), Polio is the disease that attacks us not once, but *twice*. PPS comes years later to the vast majority of both "Paralytic" and "Non-Paralytic" Polio Survivors.

And, to end on a "lighter note" . . . Some summertime humor !



Thank you for your kind words and generous donations.

We genuinely appreciate your help.

Do you have a topic you would like us to cover? Please let us know.
Always feel free to contact us.
The Pa. Polio Network Team

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