PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

June 2018

Our Mission:

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

Aging and Addiction: A Silent Epidemic

The opioid crisis is headline news all around us.
We found an interesting article about this issue and how it is affecting an aging population.

While We're on the Topic of Pain Medications –

Richard L. Bruno, HD., PhD. helps solve the puzzle on just WHY a thoughtful diagnosis is necessary before we start medicines and why Polio Survivors tend to have success when using a Rehabilitation Physician (physiatrist) for specialist care.

Another "Hot" Topic - AFib (Atrial Fibrillation)

Rehabilitation physician, William M. DeMayo, MD. addressed a question regarding two common medications being used for this issue and their impact on PPS fatigue. He will be back in July with his third article in his wonderful series "Lessons from Abroad".

Primary Care Physicians . . . We Need Them.

Both Dr. Richard Bruno and Polio Australia warn us about the tendency of Polio Survivors to blame everything on Polio/PPS. When our trusted primary care physician retires, how do we find someone new? We address the issue that so many of us are facing.

Philip Roth's Nemesis - A story about Polio in 1944.

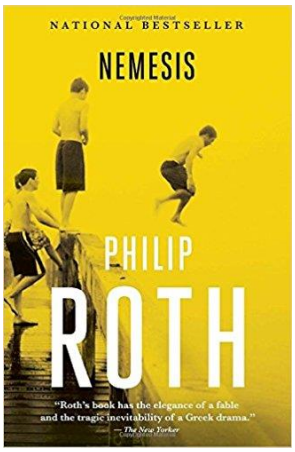
We have been wanting to highlight this book for a long time. The death of American author Philip Roth spurred us on. Thank you Kathy Galletly for this wonderful book review.

Join Team Survivor, 2018

There's never been a better time to join us. Rotary International's commitment to eradicating polio worldwide won the Best Nonprofit Act in the Hero Awards of the One Billion Acts of Peace campaign. Click HERE for the article.

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. For every dollar you give to Polio Plus (the Rotary Foundation), the Gates Foundation will triple it. A $5 donation (turned into $15 by the Gates Foundation), will result in 9 children being vaccinated against Polio. Details are available HERE our website.

Together we can make a difference.



NEMESIS:

By Philip Roth
A book review by Kathy Galletly

This story takes place during the Polio epidemic of the summer of 1944. It is centered on the character Bucky Cantor, a playground director in a park in Newark, N.J. Bucky witnesses the devastation as this terrifying disease cripples and takes the lives of the young boys on his playground.

The author describes the absolute helplessness and grief of parents who watch their young healthy children being struck down, one by one, by this awful illness. Terror takes over the city as the disease escalates. Where is this polio coming from? Who or what is causing this awful petulance? Is it the summer sun, the drinking water, the hot dogs at the local eatery, or the dirty Italian boys who spit on the ground? The terror, the anger, the frustration and the prejudice escalates. Would escaping to the Pocono Mountains in Pennsylvania be the cure?

Philip Roth was a master at capturing the horror of these terrible epidemics; you feel the escalating fear and sadness with every page. For many of us who were old enough to remember and witness the epidemics it can be a difficult read, but for me it does make me realize the survivors that we are. On a personal note - if you are aware of anyone who has a problem with vaccinating their children, suggest they read this book.

Nemesis is available through your local bookstore or online at Amazon and Barnes & Noble

Polio Australia
Improving health outcomes for Australia's polio survivors

Managing the Late Effects of Polio

A report *Identifying Best Practices in Diagnosis & Care* was another outcome of the 2001 March of Dimes Conference.[5] Polio-experienced health professionals recommend an interdisciplinary evaluation leading to a management plan that is designed specifically for the individual polio survivor.[5,6] The plan may include a variety of recommendations including:

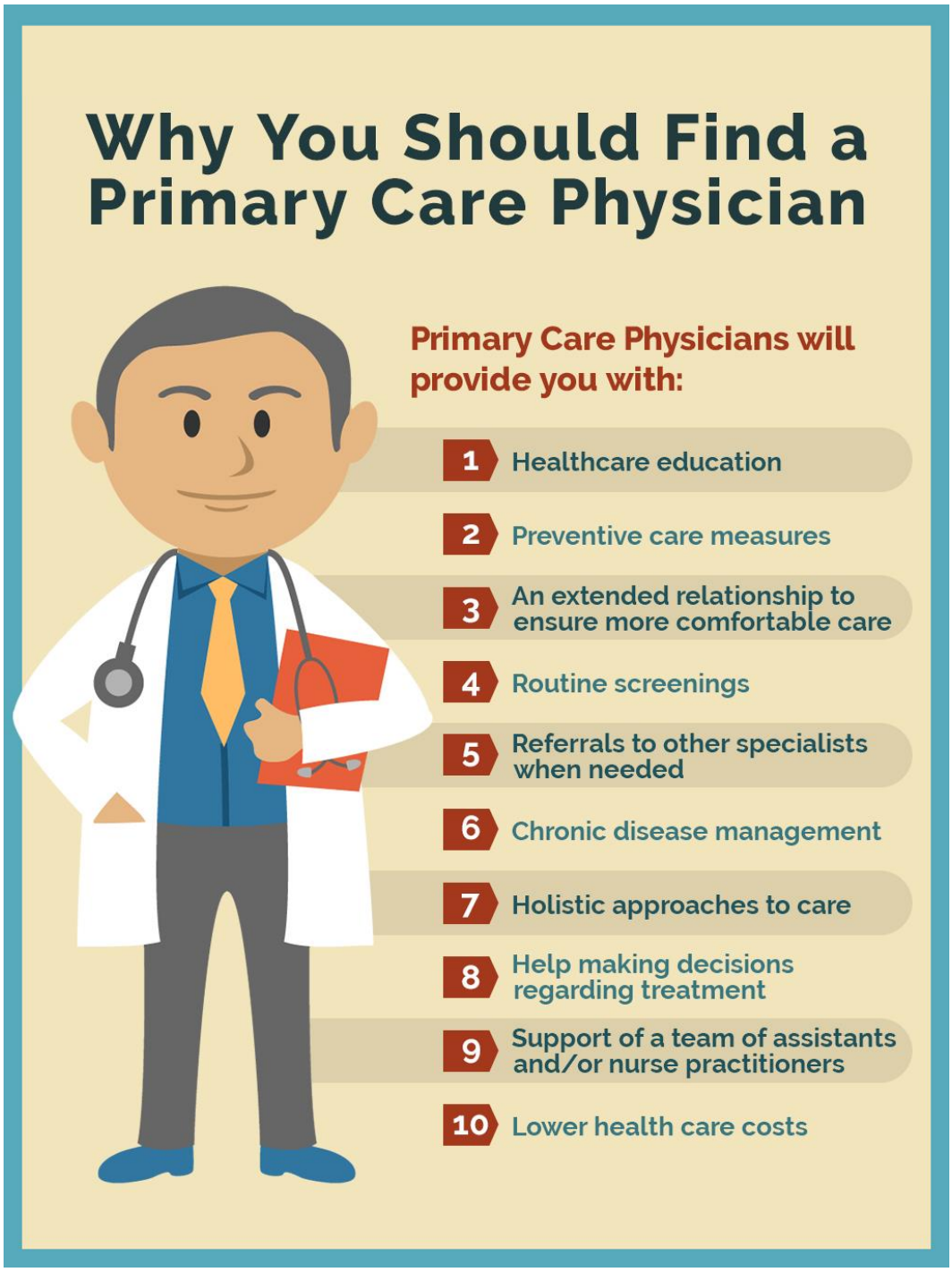
•bracing to support weak muscles and/or over-used and stretched joints;
•use of walking sticks and crutches to relieve weight on weak limbs and to prevent falls;
•customized shoes to address unequal leg lengths, which can be the cause of back pain and requires extra energy to walk;
•use of wheelchairs or motorized scooters for long-distance;
•recommendation of weight loss;
•recommendation of specific select exercises to avoid disuse weakness and overuse weakness;
•management of pain through lifestyle changes, reduction of activity, pacing, stretching, and use of assistive devices;
•use of a breathing machine at night to treat under ventilation.

Polio survivors can also help themselves by 'listening' to their bodies and 'pacing' their activities. With time, survivors can learn when to stop before they become over fatigued. Many survivors report feeling better after adopting assistive devices and interspersing activities with brief rest periods.

Finally … Be Careful When Attributing Symptoms to LEoP*/PPS

Polio conditions exist along with other diseases. Therefore, it is important not to get hung up on a diagnosis of the late effects of polio and/or post-polio syndrome. Polio survivors and their medical professionals are encouraged to work together to find the causes of any symptom and provide appropriate treatment (for example, medication for hypothyroidism, hypertension, diabetes, irritable bowel syndrome, and so on). An evaluation that too quickly determines that prior polio is the sole cause deprives survivors of potential treatments.

*Late Effects of Polio
https://www.poliohealth.org.au/late-effects-of-polio/



A primary care physician is physician who provides both the first contact for a person with an undiagnosed health concern as well as continuing care of varied medical conditions, not limited by cause, organ system, or diagnosis.

Recently, the term is primarily used in the United States. In the past in the US and still in the United Kingdom (and in many other English-speaking countries), the equivalent term was/is general practitioner.

All physicians first complete medical school (MD, MBBS, or DO). To become primary care physicians, medical school graduates then undertake postgraduate training in primary care programs, such as family medicine (also called family practice or general practice in some countries), pediatrics or internal medicine.

https://en.wikipedia.org/wiki/Primary_care_physician

Some Factors to Consider When Choosing a New Primary Care Doctor

by Eve Glazier, M.D. and Elizabeth Ko, M.D and Robert Ashley, M.D.
(April, 2018)

Dear Doctor: Our doctor is retiring, and my wife and I have been told we need to select a new physician within two months. But we read the bios of available doctors in our area who are accepted by our insurance, and their degrees are not from first-class facilities. How can we make a good selection and be assured of quality care?

Dear Reader: Finding a primary doctor is not an easy task.

You and your wife probably had a very long and good relationship with your physician. Such a relationship is not simply about treating a disease, taking care of vaccinations or providing preventive care. It's a human relationship -- one with ups and downs, but also mutual trust and a sense of comfort. So trying to replace that relationship is understandably daunting.

But let's ask: What makes a good primary doctor? It's not simply the source of the medical degree or the institution with which a doctor is associated. Those might be factors, but they might not speak to a doctor's overall quality.

If the doctor is affiliated with an institution, consider standard markers of quality about the institution itself, such as the percentage of patients getting vaccinations, colon cancer screenings, Pap smears and mammograms. Some states make this publicly available; California's Office of the Patient Advocate website is one example. Other, non-governmental websites provide patients' ratings of a doctor's care. Although multiple poor reviews could reflect poor quality of care, positive reviews don't necessarily reflect uniformly good care. Some offices encourage patients to provide good reviews, and some offices actively manage sites -- both of which can skew the results.

Then there's word of mouth. Try asking your friends, family or the people you work with for a recommendation. They may be able to give you an idea not only of a doctor's ability to diagnose and treat illnesses but also the doctor's personality. For many people, that's an important aspect of the doctor-patient relationship. Primary care doctors can be great diagnosticians, but can have personality traits that create barriers to good communication. If someone you trust attests to a doctor's ability to both communicate and to treat, this can be a powerful endorsement of his or her quality.

Another difficulty, of course, is the relative shortage of primary care physicians. After the cost of schooling and the physical and mental toils of residency, many physicians choose more lucrative specialties instead of primary care, which generally nets less income. In addition, some primary care physicians have concierge practices, meaning they accept a limited number of patients but at a higher cost to the patient.

Sometimes simply making an appointment with a new primary care doctor -- and assessing how his or her office is run -- is the only way to know whether a particular doctor will be a good fit. This may require some patience on your part. There may be some aspects of the office that you like and others that you don't, so expect an adjustment period.

But over time, you can again develop a good rapport with a doctor and have another trusted relationship for many years.

Article published with permission askthedoctors@mednet.ucla.edu

Bruno Bytes
Richard L. Bruno, H.D., Ph.D Chairperson
International Centre for Polio Education
www.post-polioinfo.com

On the topic of Pain Medications

Original Post: What pain medication do you recommend for polio-survivors? After doing some work outside in my shade garden this year I have developed new pain. Ibuprofen & Acetaminophen aren't helping at all.
Dr. Bruno's Response: You need a diagnosis before you would know what medication is needed.
Additional Post: What do you mean by "diagnosis"? Is this done by the process of elimination of other conditions? This new pain is in my joints & lower back on my weaker side, from shoulder on down. I had Polio when I was 10 and developed scoliosis at age 14. I wear a miserable back brace that probably needs to be replaced.
Dr. Bruno's Response: Diagnosis comes BY process of elimination. Typically for Polio survivors, rehabilitation physicians (physiatrists) are best because they are trained to look at the source of the pain. They or an orthopedist may send you for X-rays of your joints and your back, and maybe MRI.

REMEMBER: Not Every Symptom Is PPS!

Dr. Bruno, please explain - What IS a Physiatrist?

A rehabilitation doc (a phys-EYE-a-trist) does a medical residency learning to help people thrive with their disabilities. Physiatrists (or rehabilitation physicians), are nerve, muscle, and bone experts who treat injuries or illnesses that affect how you move. Rehabilitation physicians are medical doctors who have completed training in the medical specialty of physical medicine and rehabilitation (PM&R). Specifically, rehabilitation physicians: Diagnose and treat pain, and restore maximum function lost through injury, illness or disabling conditions. They treat the whole person, not just the problem area, lead a team of medical professionals, provide non-surgical treatments and explain your medical problems and treatment/prevention plan.

The job of a rehabilitation physician is to treat any disability resulting from disease or injury, from sore shoulders to spinal cord injuries. The focus is on the development of a comprehensive program for putting the pieces of a person's life back together after injury or disease – without surgery. Rehabilitation physicians take the time needed to accurately pinpoint the source of an ailment. They then design a treatment plan that can be carried out by the patients themselves or with the help of the rehabilitation physician's medical team. This medical team might include other physicians and health professionals, such as neurologists, orthopedic surgeons, and physical therapists. By providing an appropriate treatment plan, rehabilitation physicians help patients stay as active as possible at any age. Their broad medical expertise allows them to treat disabling conditions throughout a person's lifetime.

Bruno Bytes are updated monthly. You can find them on our website in easily accessible PDF format. www.polionetwork.org/bruno-bytes

A little bit of humor . . .

"I finally figured out the 'good ole' days'.
My pace was slower and I was faster."

Shared with us by survivor William Johnson

AFib Medications and Fatigue

A question for William M. DeMayo, MD.
DeMayo's Q&A Clinic

Question: I had polio at 3 months old - my right leg was affected. Now I'm 65 and have PPS. I have AFib (Atrial Fibrillation) and was put on Eliquis and Metropol.

Can either one of these medications cause pain and make you tired all time? I've always had fatigue issues. It seemed to get worse after taking these two medications. It's very difficult, as you know, to find someone who knows about PPS.

Answer: In short, Yes !

Your medications and medical condition can certainly be causing your fatigue. In fact if functional loss is primarily from fatigue and there is not clear focal weakness and atrophy that has worsened in recent years the issues could be entirely medical and not PPS at all. Since I don't have a full history, I am simply saying that to emphasize the functional impact of the medical issues at hand rather than to say PPS is not the cause (that is a specific diagnosis that needs to be between you and your treating physician).

Atrial fibrillation is an uncontrolled rapid and irregular beat of the Atrium (top chamber) of the heart. Contractions can be so quick that the actual pumping of blood is affected leading to the risk of developing a clot in the Atrium that could later be pumped out into the circulation and cause a stroke. This risk is addressed by the Eliquis (an oral blood thinner). Eliquis itself has few side effects but the big concern is uncontrolled bleeding - it is an important drug to be aware of but not pertinent to your current complaints. Metoprolol on the other hand has common side effects of fatigue, sleep disturbance and even depression. It is meant to slow the heart and counteract the potential rapid heart rate of the AFib. If mild, these are sometimes symptoms that need to be tolerated since the rapid heart rate can be a bigger issue. This risk/benefit ratio is very patient specific and well beyond the scope of this reply. Nevertheless, it is certainly possible that the fatigue is entirely due to metoprolol and this should be discussed with a cardiologist. Sometimes other medications are available OR a simple dose adjustment is needed.

Lastly, Atrial Fibrillation can occur in isolation but also can occur in the setting of heart valve issues or coronary heart disease. You have not mentioned those diagnoses but, if present, they can also clearly contribute to fatigue and loss of function due to ineffective cardiac output (the amount of blood pumped out with each beat).

In summary: Yes, medications can certainly be playing a role and risks/benefits of medications in this setting is very individualized and best addressed between the patient and their PCP (primary care physician) or cardiologist.

On a separate but related note, it struck me that you were not aware that Metoprolol causes this side effect. There are easily accessible resources online and it certainly something your pharmacist could tell you about. It is surprising that your prescribing physician did not mention it or you did not recall that he did. (Additionally, I am making a presumption that you did not bring up the fatigue as a clear issue and ask about the medication). This might be a situation where you have a doc who is just not taking the time OR that you are not clearly organizing your concerns and questions in advance, Often it's a combination of both. Either way, I am certain that your PCP or cardiologist will engage this once you bring it to their attention. If you are not satisfied with the response after a couple of attempts, then it might be a good idea to seek care elsewhere.

I hope this helps. Warm Regards from my temporary home in the UAE.

Aging and Addiction: A Silent Epidemic

From Web MD

There is no one face of addiction; it affects individuals from every demographic regardless of gender, age, religion, race or socioeconomic status. Despite this, there is a prevailing misconception that older adults are not as vulnerable to substance abuse. Research, however, shows that addiction in the elderly—adults 65 and older—is a growing problem that is often underdiagnosed and, therefore, undertreated.

Addiction Causes

Older adults are particularly at risk for prescription drug abuse because they are more likely to take medications to address co-occurring and age-related conditions. These drugs, which often have a high potential for addiction, include:

•Opioids – used for pain management, examples are oxycodone, fentanyl, and morphine.
•Stimulants – used to enhance brain activity, examples are amphetamines and methylphenidate.
•Benzodiazepines – used to treat anxiety and insomnia, examples are diazepam, chlordiazepoxide HCI, and alprazolam.

Prescription drug abuse occurs when an individual misuses the medicine in a way that is not instructed by their doctor—such as, taking more medication than prescribed or mixing the drug with alcohol.

The concurrent use of different medications is frequent among older adults. According to the Substance Abuse and Mental Health Services Administration (SAMHSA), 30 percent of people ages 57 to 85 take at least five prescriptions, increasing the risk of unintended drug interactions and dependency.

In addition to the increased availability and accessibility of prescription drugs, as a person gets older, their body changes. These changes can impact the way they absorb and filter medicine, making them more vulnerable to addiction than a younger adult.

Many older adults are also going through stressful life changes, such as the death of a spouse, development of a chronic illness, and decreased mobility, all of which can contribute to depression and substance abuse.

Consequences

The abuse of prescription drugs impacts the overall health of older adults in several ways. Patients increase their chances of falling or having an accident, and they can worsen neurological, respiratory, and other age-related conditions. Overall, patients who abuse prescription drugs tend to have higher rates of morbidity.

Signs of Addiction

Family members, caretakers, and health care providers frequently mistake the signs of drug abuse for other physical and mental disorders associated with age. Older adults are also more likely and able to hide their substance abuse as they are often retired and not prone to getting in trouble with the law, so there are seemingly less negative consequences to their behavior.

If you are concerned, here are some signs to watch out for:

•Use of the medicine outside of the doctor's instructions.
•Seeking a prescription from multiple doctors or filling an order at multi pharmacies.
•Behavior changes, such as becoming angrier or withdrawing from everyday activities.
•Defensive about and making excuses for taking the medicine.
•Hiding the medication.
•Previous substance abuse problems.

What You Can Do

As the "Baby Boomer" generation continues to age, it is expected that prescription drug abuse in the elderly will also rise. The good news, according to addiction specialists, is that with the proper treatment, this population has the highest rates of recovery of any age group. There is help, and there is hope.

https://www.webmd.com/dna/the-journey-starts-now?ecd=socpd_fb_nosp_7002_spns_cm954#aging-addiction

Post-Polio Syndrome and Polio and the Polo Vaccine

by Dr. Colin Tidy

Post-Polio Syndrome. This is an outstanding article from the UK, designed for Health Care Providers and understandable by patients as well.

There is a 2nd equally well done article referenced about *Polio and the Polio Vaccine* by Dr. Colin Tidy.

Thank you **popsycle** for bringing these outstanding articles to our attention.

Looking for information from Dr. Bruno on a specific topic?
Check out the "Bruno Bytes" Index by Subject
It's available by direct "link" **HERE**
Or
Underneath the current "Bruno Bytes" on **this page** of our website.

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

Unless noted with the article, feel free to copy and share what you see. Always give credit to the original source, include a working link to our website: www.polionetwork.org
(or) the specific page on our website where noted and email us a copy of what you "share".
THANKS.

Contact us: Email: info@polionetwork.org Phone: 215-858-4643
PO Box 557, Doylestown, Pa. 18901
We are a Registered 501C3 organization