



PA Polio Survivors Network

Information and Inspiration for Polio Survivors and
Their Families

From the Keystone State and Beyond

www.polionetwork.org

November 2016

Our Mission:

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

Healthy Healing Relationships and Sleep

(Sleep even when our legs just won't stop moving)

This month, we are continuing our series by [William M. DeMayo, MD.](#) on the importance of healthy sleep. [Richard L. Bruno, HD, PhD.](#), and Post-Polio Health International have shared interesting articles with us about Healthy Relationships as they apply to Healing and Pain Management. Additionally, we are thrilled to have received an article from Polio Southern Australia who published it when our contributing physician, Dr. DeMayo spoke there in September.

(Parts 1 and 2 of our "sleep" series were in our Sept. and Oct. newsletters and are easily available on our website.

Without question, one of the most critical things we've learned in our journey to publish accurate information is the statement by Richard L. Bruno, PhD. at the Post-Polio conference in our State last year. "Polio Survivors – you are all the same and you are *all* different". This quote is significant as we go forward with our work.

We all hear about "exercise" and PPS. Dr. Bruno's message spoke to us on this topic. There is no magic pill for what we have. We must each follow our own journey to determine our physical limitations – hopefully guided by a well informed, PPS knowledgeable physician and physical therapist.

This year's 2016 PHI Photo contest winner is the best example we've seen as to how we can show how a polio survivor has learned how to adjust his behavior and thus reduce his regular exercise as to not worsen his PPS symptoms. Thank you Bruce Lessard.



"I can't train and race bikes like I used to, having had to cut back on the training intensity to avoid right leg pain that started occurring in my 50s, which was a suggestion from Dr. Maynard of Post-Polio Health International. That doesn't mean I need to quit. Instead, I'm making adjustments. I've learned two things:

- (1) too much exercise causes right leg pain, and may contribute to more serious problems down the road; and
- (2) inactivity actually leads to pain in my right leg, but a low to modest amount of exercise actually helps to keep my right leg pain-free. So, I can still enjoy activities with my family, like mountain biking with my granddaughter.

I realize I'm pretty lucky compared to many people with Post - Polio Syndrome."

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WE'RE STILL HERE! was established in 2007 by Post-Polio Health International (PHI) as an annual campaign to educate the healthcare community and the public that there are survivors of polio still in need of health care and still making the world a better place for all people with disabilities."



Bruno “Bytes”

(Q&A's from Richard L. Bruno, HD, PhD)

Bruno Bytes are updated regularly, and are available in their entirety through a “link” on www.postpolioinfo.com (or) directly through polionetwork.org/bruno-bytes

On the topic of the Healing Power of Relationships (10/17/2016)

Dr. Bruno's Original Post: Don't Scoff at the Placebo Effect. Relationships are Healing. . .

Study Finds Knowingly Taking Placebo Pills Eases Pain

“Fake pills” significantly reduced pain and disability in patients with chronic low back pain

Newswise — BOSTON – Conventional medical wisdom has long held that placebo effects depend on patients' belief they are getting pharmacologically active medication. A paper published today in the journal *Pain* is the first to demonstrate that patients who knowingly took a placebo in conjunction with traditional treatment for lower back pain saw more improvement than those given traditional treatment alone. “These findings turn our understanding of the placebo effect on its head,” said joint senior author Ted Kaptchuk, director of the Program for Placebo Studies and the Therapeutic Encounter at Beth Israel Deaconess Medical Center and an associate professor of medicine at Harvard Medical School. “This new research demonstrates that the placebo effect is not necessarily elicited by patients' conscious expectation that they are getting an active medicine, as long thought. Taking a pill in the context of a patient-clinician relationship – even if you know it's a placebo – is a ritual that changes symptoms and probably activates regions of the brain that modulate symptoms.”

Kaptchuk, with colleagues at Instituto Superior de Psicologia Aplicada (ISPA) in Lisbon, Portugal, studied 97 patients with chronic lower back pain (CLBP), which causes more disability than any other medical condition worldwide. After all participants were screened and examined by a registered nurse practitioner and board certified pain specialist, the researchers gave all patients a 15-minute explanation of the placebo effect. Only then was the group randomized into one of two groups; the treatment-as-usual (TAU) group or the open-label placebo (OLP) group. The vast majority of participants in both groups (between 85 and 88 percent) were already taking medications – mostly non-steroidal anti-inflammatories (NSAIDs) – for their pain. (Patients taking opioid medications were excluded from the trial.) Participants in both the TAU and OLP groups were allowed to continue taking these drugs, but were required not to change dosages or make any other major lifestyle changes, such as starting an exercise plan or new medication, which could impact their pain. In addition, patients in the OLP group were given a medicine bottle labeled “placebo pills” with directions to take two capsules containing only microcrystalline cellulose and no active medication twice daily.

At the end of their three-week course of pills, the OLP group overall reported 30 percent reductions in both usual pain and maximum pain, compared to 9 percent and 16 percent reductions, respectively, for the TAU group. The group taking placebo pills also saw a 29 percent drop in pain-related disability. Those receiving treatment as usual saw almost no improvement by that measure. “It's the benefit of being immersed in treatment: interacting with a physician or nurse, taking pills, all the rituals and symbols of our healthcare system,” Kaptchuk said. “The body responds to that.” “Our findings demonstrate the placebo effect can be elicited without deception,” said lead author, Claudia Carvalho, PhD, of ISPA. “Patients were interested in what would happen and enjoyed this novel approach to their pain. They felt empowered.”

Kaptchuk speculates that other conditions with symptoms and complaints that are based on self-observation (like other kinds of pain, fatigue, depression, common digestive or urinary symptoms) may also be modulated by open-label treatment. “You're never going to shrink a tumor or unclog an artery with placebo intervention,” he said. “It's not a cure-all, but it makes people feel better, for sure. Our lab is saying you can't throw the placebo into the trash can. It has clinical meaning, it's statically significant, and it relieves patients. It's essential to what medicine means.” “Taking placebo pills to relieve symptoms without a warm and empathic relationship with a health-care provider relationship probably would not work,” noted Carvalho.

<http://www.newswise.com/articles/view/662854/?sc=mwhn>

Restless Leg Syndrome (RLS) & Periodic Leg Movement Disorder (PLMD)

Article #3 in the series about Sleep

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

Question: Do many other post polio patients have restless leg syndrome?
How is it usually treated?

This recent question from a reader ties perfectly into our multipart series on sleep. As you will recall, Part I* discussed insomnia and problems caused by lack of restful sleep. Part II* discussed Sleep Hygiene and outlined habits that can improve quality and quantity of sleep. This month we will talk about one of several underlying sleep disorders. When discussing sleep disorders, it is important to understand that most individuals do not have either a problem with Sleep Hygiene or an underlying sleep disorder. It is usually an “and/both” situation - most individuals with underlying sleep disorder also have problems with Sleep Hygiene. So before specifically talking about specific treatment of Restless Leg Syndrome (RLS) & Periodic Leg Movement Disorder (PLMD), I want to emphasize that good Sleep Hygiene is imperative for an optimal outcome. Given the fact that old habits die slowly, it may be helpful to review Part II* of our series multiple times.

So what does RLS have to do with sleep? The answer is “A Lot!”. Since part of the definition of deep sleep is lack of muscle movement, anything that prevents muscle relaxation can prevent deep sleep. PLMD is a variant of RLS in which there is a neurologic drive for movement which battles the body's drive for complete muscle relaxation/deep sleep. If the PLMD wins then an individual may have multiple awakenings or simply a very poor quality sleep, leading to all the consequences we discussed in Part I* of our series. Interestingly, lack of sleep can make RLS/PLMD even worse, leading to a “snowball effect”. This also highlights the importance of Sleep Hygiene and some individuals with a tendency towards RLS/PLMD may need no further treatment than to improve their Sleep Hygiene. Similarly, there is a significant overlap with Sleep Apnea and PLMD such that treating the sleep apnea may lead to resolution of the PLMD.



Since Sleep Apnea and suboptimal Sleep Hygiene are quite prevalent in the post polio population, it is no wonder that RLS/PLMD is quite prevalent. Additionally, there have been theories that fatigue plays a role in creating neurologic changes in the brain that facilitate RLS/PLMD. Excessive fatigue and Post-Polio Syndrome could, therefore, be another factor increasing prevalence of this problem. The exact prevalence is hard to determine and experts can argue different figures. A very brief review of literature showed studies have been small but some have noted a prevalence of RLS/PLMD as high as 63.6% in the polio population (7.5% in “healthy controls”). Another uncontrolled study showed a prevalence of 40.4% in polio survivors .

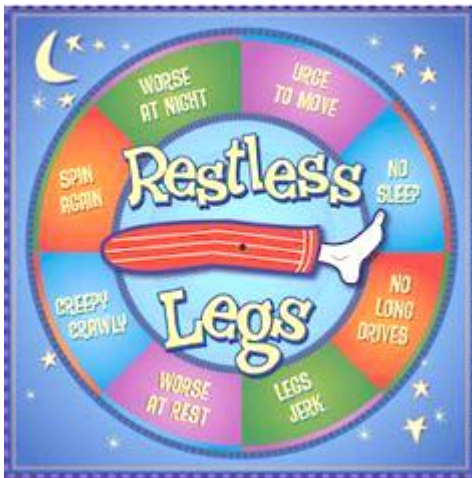


It is widely accepted that RLS/PLMD is likely underdiagnosed in the general population. My personal opinion is that most of us have an underlying tendency towards this condition, which can be “uncovered” at different times in our life in different stressful circumstances.

So what exactly are RLS and PLMD? Both are neurologic conditions. PLMD, in simplistic terms, can be thought of as a nighttime cousin of RLS. Up to 80% of individuals with RLS also have PLMD but the reverse is not true and many individuals with

PLMD do not have RLS. PLMD can be objectively measured in a sleep laboratory using electrodes over the muscle. Diagnosis of RLS on the other hand, is based on history and symptoms. A strong family history can also aid in the diagnosis. RLS is often unrecognized or misdiagnosed, especially when symptoms are mild or intermittent yet, other cases of RLS are quite obvious. The hallmark symptom of RLS is an irresistible urge to move which worsens at rest or when laying down. It is important to stress that the urge comes first and is followed by voluntary movement. This is in contrast to movement which is involuntary such as muscle twitching or spasm. Some individuals also complain of “itchy”, “pins and needles” or “creepy crawly” feeling in their legs. I have also had patients complain of intense aching in their legs, although this is much less common.

Restless leg syndrome is more common with other, more common, chronic diseases and medical conditions including Parkinson’s disease, kidney failure, diabetes, and peripheral neuropathy. Iron deficiency can also cause RLS and iron levels should be checked for this reversible problem. Some medications can also aggravate symptoms (check with your pharmacist) as can alcohol or caffeine.



Treatment of RLS/PLMD depends upon the severity. It is always important to address the above underlying causes first and to address Sleep Hygiene (see Part II article*). For more significant cases medications are indicated. Many primary care physicians use “dopaminergic” medications such as Mirapex or Requip and these can be quite effective. I personally favor medications such as Lyrica, Neurontin, or Horizant. The latter is newer (and more difficult to obtain) but very effective. In the past, physicians used narcotics or Valium type medications. I avoid the use of these medications unless we determine them to be absolutely necessary." Given the intermittent nature of these neurologic conditions, I always encourage periodic “drug holidays” to see if the medication is still needed and close

monitoring to see if dosages need to be restarted or increased. Seasonal changes and personal stress issues that affect fatigue and sleep can profoundly impact these conditions and a holistic approach might include initial medical management to control the problem with a long term goal of transitioning to nonpharmacological methods of avoiding stress and sleep deprivation.

[William M. DeMayo, MD](#)
November, 2016

***Parts 1 and 2 of Dr. DeMayo’s “Sleep” Articles were in our September and October, 2016 Newsletters. You can see the full series on our website – [DeMayo’s Q&A Clinic](#)

1 Eur J Neurol. 2015 Mar;22(3):472-8

2 Kumru H, PortelE, Barrio M, Santamaria J. Restless legs syndrome in patients with sequelae of poliomyelitis. Parkinsonism Relat Disord (2014)20(10):1056-8

Do you have a question for Dr. DeMayo?

Email us at: infopolionetwork.org

Dr. DeMayo has more than 30 years of clinical experience in the field of Physical Medicine & Rehabilitation. He has served as Medical Director for several comprehensive inpatient rehabilitation units and has also maintained an active outpatient practice.

New Research Summary: Having Good Relationships with Care Coordinators can Improve Experiences with Managed Care

<http://agerrtc.washington.edu/node/265>

What was this research about?

Recently, many Medicaid programs have begun following a “managed care” model for their coverage. This means that their healthcare is coordinated through a single managed care organization. Some Medicaid enrollees, especially those with more complex health needs, are assigned a care coordinator when they sign up for Medicaid. The care coordinator, like a case manager, works with the enrollee to develop a personalized healthcare plan and helps the enrollee access needed services. Care coordinators could be of great assistance to Medicaid enrollees with disabilities, who may have complex healthcare needs. In this study, we wanted to see if the quality and quantity of contact people with disabilities had with their care coordinator was related to their healthcare satisfaction or their unmet healthcare needs.

What did the researchers do?

Researchers at the University of Illinois at Chicago sent surveys to Medicaid enrollees with disabilities who were receiving managed care. The researchers focused on surveys from 442 respondents who had been assigned a care coordinator. The survey asked respondents to rate the quality and quantity of contact they had with their care coordinator. To measure quality, the respondents indicated how much their care coordinator knew about their personal medical history, how often the coordinator took their wishes into account when developing care plans, and how much input they had in their care planning. To measure quantity, the survey asked respondents how often their care coordinator called or visited them to follow up on their healthcare needs. Then, to find out how quality and quantity of contact was related to overall care satisfaction, the respondents answered survey questions about how satisfied they felt with their healthcare overall and specifically from their primary care doctor and specialists. The respondents also indicated if they had any “unmet needs”, or specialty services they needed but couldn’t get from their health plan. Finally, the respondents answered questions about their background and disability type.

What did the researchers find?

Overall, most respondents were happy with their care coordinators, and they felt that their coordinators understood their medical needs and took their wishes into consideration. Respondents who felt they had better-quality relationships with their care coordinators were happier with their healthcare and had fewer unmet needs than those respondents who reported less positive relationships. The frequency of coordinator contact, however, was unrelated to respondent satisfaction or unmet healthcare needs.

There were also differences between disability types: Respondents with intellectual/developmental and respondents with mental health disabilities were less satisfied with their healthcare than respondents with physical disabilities. Respondents with mental health disabilities reported having more unmet needs than those with intellectual/developmental or physical disabilities.

How can you use this research?

- Care coordinators can provide “person-centered” care by building relationships with patients and valuing their wishes and input. When this happens, patients are more satisfied with their care, which can lead to better outcomes and lower costs.
- Training in communication skills and disability-specific issues may help improve relationships between care coordinators and their patients with disabilities.
- Although patients were happy in general with the services they received under Medicaid Managed Care, those with mental health and intellectual/developmental disabilities were less satisfied. Improving care for these disability groups, who may have more complicated healthcare needs, is an important area for Medicaid managed care programs to address.

Things you should know:

To learn about changes in Medicaid programs, go to: www.medicaid.gov(link is external)

To learn about your eligibility for benefit programs, including Medicaid, go to: www.benefits.gov

Source: <http://agerrtc.washington.edu/node/265>

Technical difficulties didn't stop the show when US-based Dr DeMayo, a specialist in physical medicine and rehabilitation spoke to a full house for Polio SA in Glenunga on Sunday 18th September.



Peter Weirenga, Dr. DeMayo, Dr. Nigel Quadros
and Brett Howard

The event preceded his keynote talk at the 2016 Australasia Pacific Post-Polio Conference in Sydney on 20th to 22nd September. After he spoke, Dr. DeMayo was joined by Dr Nigel Quadros from the Queen Elizabeth Hospital for a Q&A session.

Working without the aid of his PowerPoint presentation, Dr. DeMayo's information about pain management and rehabilitation was not what some might have expected – his holistic, multidisciplinary approach involves very little in the way of narcotics use.

In fact, he's much more interested in trying to get to the root cause of a problem to prevent the need for drugs, as opposed to masking the symptoms. And he also encourages clients not to underestimate the power of spirituality and optimism during the rehabilitation journey.

Don't throw the baby out with the bathwater. Build on what works.

Dr. DeMayo talked about how he sees a lot of clients starting one rehabilitation modality and then stopping it, in favour of another – a practice he thinks is unwise. "Don't throw the baby out with the bathwater," he urged, meaning that it's important to build on rehabilitation work that has been useful in other areas then combine it with advice from another.

Dr. DeMayo's own multidisciplinary approach is very individualized. It builds on, and compliments, other approaches and experiences. In his practice he works with physiotherapists, nurses, orthotists, speech therapists, occupational therapists and exercise therapists to tailor solutions for his clients. He encourages people with post-polio syndrome to never stop trying to find ways to manage the condition through medical, alternative and complimentary medicines like aromatherapy, massage, yoga, water massage.

In recent years, yoga is an exercise form he has been really impressed with in with his clients. "Yoga in post-polio is non-fatiguing, and stress lowering," he said. *However*, he warned, it's important that the yoga instructor has an understanding of modifying poses to suit an individual's ability and pain threshold.

Tap into your own brand of spirituality

One of the points Dr. DeMayo spoke at length about, was the importance of spirituality and optimism in an individual's rehabilitation. It doesn't matter what you believe in, he just encourages you to tap into it because he sees greater results in pain management and rehabilitation with individuals who do. "It's a mistake not to include spirituality – or whatever puts you in touch with a higher power when dealing with sleep problems, stress and pain," he said.

Similarly, he advises individuals to pay attention to their thoughts and words. "Saying 'I can't' is extremely disabling. Quoting the wise words of Henry Ford, "Whether you think you can do a thing or think you can't do a thing, you're right," he said. And Dr. DeMayo says, it's the same with

post-polio syndrome. Words like “I need to”, “I have to” and “I should” leave us stuck in the corner feeling guilty when they can’t be achieved, leading to further stress or sleep problems.

He suggests, instead, replacing this thinking with “I want...” or “I’ve got a difficult choice”.

He adds that insomnia, stress, anxiety and lack of peace, make the cycle of pain much worse, in the way that gasoline feeds a fire. So it’s important to use whatever techniques are available to help keep these aggravating factors at bay – another reason why he believes spirituality and optimism to be so crucial.

Set Goals and Know your Limits

Self-empowerment and limit setting are critical, according to DeMayo. It’s important that individuals ask themselves what they can do to relieve their pain or increase their function. This is because here’s a limit to how much activity each individual can achieve and it is impeded by inactivity, over-activity and age. He said it’s important to listen to the body and modify activity based on how you feel during and afterwards activity. You don’t want a life that revolves around activity and depletes you any more than a life as a couch potato. There’s a middle ground and it can shift if your activity is in the right zone.

“Many folks with Post-Polio overdo it. We want people to work at capacity, not over. So in order to do that we have to cross the line slightly to work out where it is...but not by much,” he said. Once you regularly reach your limit, you’ll find that it shifts, and you may be able to do more.

Dr. DeMayo’s complete inventory of articles (and) videos are available: [DeMayo’s Q&A Clinic](#)



Survivor Donna Aragon Finishes



We are “This Close” to Ending Polio



Survivor Jim Smith and his wife Mary, at the finish.

On October 22nd, five Polio Survivors, family members and friends attended the Purple-Pinkie Walk/Run on your behalf. It was a cold, wet, wonderful day. In spite of the weather, two from our Team Survivor braved the cold and crossed the finish line!

We are thrilled to report that “Team Survivor” raised \$2,756 in donations. Your checks came from all over the United States – from survivors, family members, post-polio support groups and friends. With the Gates Foundation participation (2 for 1 match) an additional \$5,512 was added to this amount. Your donations have raised a total of \$8,268.00 for the Rotary Foundation’s Polio Plus Campaign !

It is an expensive process to get the vaccine into the dangerous areas of the world where it is needed. Rotary International, the Gates Foundation, Unicef and the World Health Organization are working tirelessly to make this happen. Your generosity has resulted in Polio vaccines for 8,268 children that would have otherwise gone unvaccinated.

There are two outstanding videos on our website. Take a look and see the work your donation is supporting.

Thank you for being part of such a worthwhile project. We are “This Close” to Ending Polio.

Without question, the one thing we all share is the prayer that through world wide vaccination, death and disability from the Polio Virus will soon be goneFOREVER.

For multiple pages of information about Post-Polio Syndrome:

Check out this section of our website:

polionetwork.org/living-with-post-polio-syndrome

Check out all the articles written by Dr. William DeMayo, MD., and the entire collection of “Bruno Bytes” from the International Centre for Polio Education on our [website](#)

Send us YOUR photo for our slide show of Survivors.

info@polionetwork.org

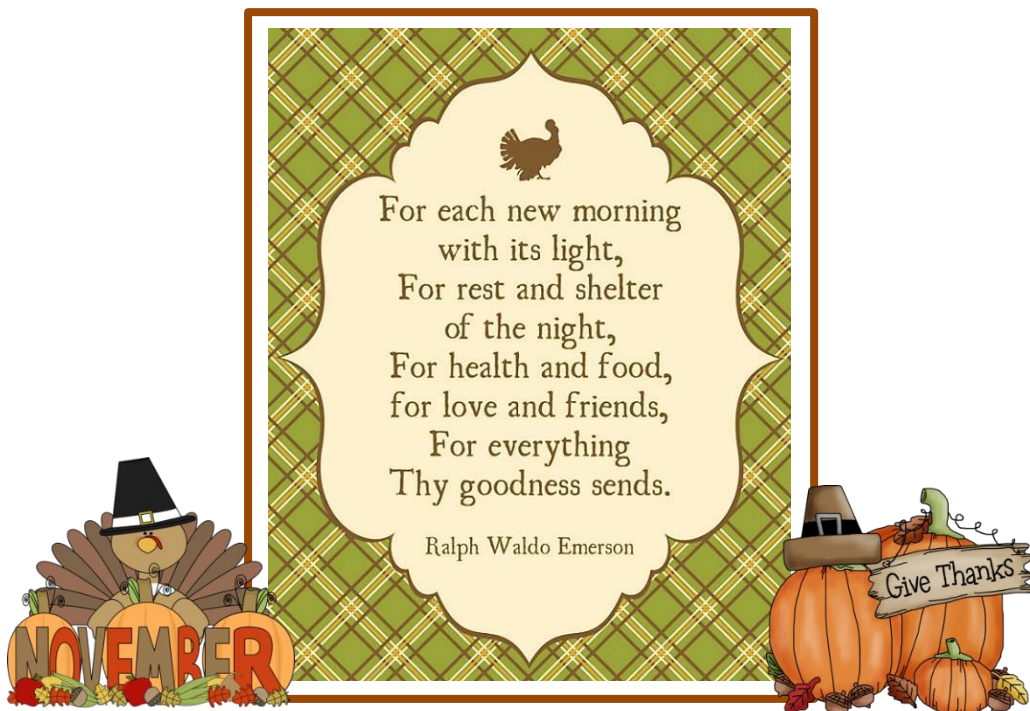
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Details are available here:

polionetwork.org/contact

Thank You!

We are truly grateful for your kind words of support and very generous [donations](#) that will help our work continue.



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You are *not* alone. We're here to help.



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