



PA Polio Survivors Network

Information and Inspiration for Polio Survivors and
Their Families

From the Keystone State and Beyond

www.polionetwork.org

December 2017

Our Mission:

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

It's hard to believe that another year is coming to an end.

For so many of us, with that comes winter – which can be long and cold.

Winter Wellness is of greatest importance.

We are grateful to the International Centre for Polio Education, Post-Polio Health International and [William M. DeMayo, MD.](#) for helping us sort through the “pros & cons” and “good and bad” of the issue of adjusting to the new season of cold weather combined with the fatigue that often follows the holiday season.

“Bruno Byte” Tips that include “Finding Words” and Flu Vaccine Pros & Cons

This month, [Richard L. Bruno, PhD.](#) revised an article of great importance on the issue of Polio Survivors experiencing “Word Find” issues that are so often a result of fatigue. He gave us a more “user friendly” version for this newsletter of the formal research article that he and Dr. Jerald Zimmerman, MD published in the American Journal of Physical Medicine and Rehabilitation.

For those of us who experience this PPS issue, this shortened version is easily shared with our physicians. Thank you Dr. Bruno.

In addition, he has shared a terrific “Tip” from the University of Alabama regarding the Flu Vaccine.

Are you Seeking a New Health Care Provider?

With the new year often comes changes in those who care for us.

In their manual of [Post-Polio Health Care Considerations](#), PHI has published an outstanding guideline for those seeking Professional Assistance. Dr. William DeMayo would like to remind us to seek professional assistance from a Health Care Provider who truly has the “Heart of a Teacher”.

Post-Polio Care: Past, Present and Future

[William M. DeMayo, MD.](#) and [Daniel J. Wilson, PhD.](#) shared a wealth of wisdom about Post-Polio Care and how care history from the past has affected our PPS care today.

Their conversation(s) gave us the information we need to be more informed and thus be able to help ourselves more effectively.

We are grateful to a truly humble NJ Polio Survivor whose talent in video editing is a true gift.

The Conference video – available in 3 parts is available:

[Dr. DeMayo](#), [Dr. Wilson](#) and the Q&A with both.





As people age, it can become harder for the body to fight off illness and fully recover. The immune system weakens and other conditions can complicate a cold or the flu. Taking steps to stay

healthy and protect against illness (as much as possible) is essential for all of us, especially seniors. From eating right and staying active to avoiding certain situations, there are many ways seniors can be proactive.

Get Vaccinated.

If you and your loved ones haven't already been vaccinated, now is the time. Adults age 65 and older can get a "high dose vaccine" to provide even more immune support and protection. Remember that it takes about two weeks for the vaccination to become fully effective, so still take care around individuals who may be sick. While getting a flu shot won't guarantee that you won't get sick – it only protects against certain strains of the flu, it can help reduce your risk.

Rest Up.

Give your body plenty of time to rest and recover, especially if you are feeling worn down. Pushing too hard can stress your body and weaken your immune system making you more susceptible to illness. Sleep allows your body to heal and recharge, fighting off germs. Avoid individuals who are sick. As much as you want to see your grandchildren or visit with friends, if someone is ill, try to stay away until they are feeling better. Limiting your exposure to germs can help you stay healthier. In the meantime, consider using FaceTime, Skype, or another digital platform to stay in touch without sharing germs.

Wash Your Hands.

This is an effective way to reduce the spread of illness if you are vigilant about it. After you've been out in public, touched common items, or spent time around a lot of people, it's a good idea to wash your hands and even change your clothes. If you can't get to a sink, keep some hand sanitizer in your bag or car. Try to avoid touching your face as much as possible because the eyes and mouth are prime entryways for germs.

Eat Right.

Make sure you are eating a well-balanced diet that includes plenty of fresh fruits and vegetables and lean protein. This can help boost your immune system. If you can't find fresh produce, frozen is okay too.

Stay Active. Regular exercise (based on your personal limitations) can help to stimulate your immune system, sweat out toxins, and keep illness at bay. It also supports stress management – too much stress can weaken your immune system. It's great to go outside and get fresh air, but make sure to bundle up.

<https://www.alwaysbestcare.com/pa/upper-buxmont/>



Everyone expects
“Ho-Ho-Ho”
Sometimes it's okay to
say **“No-No-No”**



Bruno “Bytes”

Q&A with [Richard L. Bruno, HD, PhD](#)
Director, International Centre for Polio Education

The Flu and Pneumonia Vaccines (10/30/2017)

Dr. Bruno’s Original Post: Here is something to think about and talk to your local doctor about from the University of Alabama.

There is no Polio or PPS reason not to be vaccinated against flu or pneumonia.

Always get vaccines from your DOCTOR who knows your history, not the person in the pharmacy.

Flu Season is Here

The contagious respiratory illness caused by viruses that infect the nose, throat and lungs can cause mild to severe illness and at times may lead to death. People of every age — including people in good health — are at risk for flu. Approximately 970,000 Americans were hospitalized due to the flu in 2014, and more than 40 million were affected by flu-related illnesses, according to the Centers for Disease Control and Prevention.

Although a majority of hospitalizations and deaths occur in people 65 years and older, even healthy young children and younger adults can have severe disease or even die from influenza. Nearly 100 deaths from influenza among children are reported each year to the Centers for Disease Control and Prevention. These data, say UAB experts, are reason enough for Americans to receive their yearly influenza vaccine.

The most common symptoms of the flu are fever, chills, fatigue, muscle aches, stuffy or runny nose, and sore throat, and symptoms typically last a week. A wide range of complications can be caused by influenza virus infection of the upper and lower respiratory tracts. Complications of flu can include bacterial pneumonia, ear infections, sinus infections, dehydration and worsening of chronic medical conditions, such as congestive heart failure, asthma or diabetes.

Forecasting Flu Season: Recent reports show that Australia has seen its worst flu season on record. Kevin Harrod, Ph.D., the Benjamin Monroe Carraway Endowed Chair and professor in the UAB Department of Anesthesiology and Perioperative Medicine, says what happens in the southern hemisphere is usually indicative of what type of flu season will occur in the northern hemisphere.

“These data tell us that we should see a worse than average flu season,” Harrod said. “But, with all things influenza, there’s a lot we don’t know.” Harrod says this year’s vaccines are combating the H3N2 strain and B strains of influenza. He added that H3N2 viruses cause worse disease in the elderly and young children, and that they are associated with a high hospitalization rate.

With all the knowledge and scientific research about influenza, Harrod says it is extremely difficult to perfectly forecast which strains are used to create vaccines. “There are always a few strains circulating that aren’t predominant, but can become predominant — especially in populations of high immunization,” he said. “So, it’s difficult for public health officials to predict which strains will circulate. For that reason, not every vaccine is a perfect match.”

Vaccines for Everyone: In his lab, Harrod — who has been studying influenza and other respiratory viruses for 20 years — and his team research the effectiveness and development of novel antivirals against influenza. Because it is ever-changing, scientists are always looking for new and better ways to fight the severity and frequency of influenza.

Harrod says the best way to prevent flu from spreading and becoming more serious is by getting vaccinated. “While getting the flu shot may not keep you from getting the flu, it will limit the severity and duration of the illness, and provide you with some protection against future infections in subsequent seasons,” Harrod said. “Even in years when the flu vaccine is a ‘bad match,’ there is partial protection because one’s immune system can make antibodies that still recognize and bind to the influenza virus even when new strains emerge unexpectedly.”

The Complete Article is available here:

<http://www.newswise.com/articles/view/683856/?sc=mwhn>



WORD FINDING DIFFICULTY AS A POST-POLIO SEQUELAE

(Rev. 2017: Abbreviated from the original)

By: Drs. [Richard L. Bruno, PhD.](#) and Jerald R. Zimmerman, MD.

The Post-Polio Institute and
The International Centre for Post-Polio Education and Research

Of all Post-Polio Sequelae, fatigue is the most commonly reported and most debilitating symptom. In the 1985 National Post-Polio Survey, 91% of respondents reported new or increased fatigue, 41% reported fatigue interfering with performing or completing their work and 25% reported fatigue interfering with self-care activities (1-5)*. Importantly, polio survivors differentiate between physical tiredness and what they describe as "brain fatigue" associated with thinking difficulties. In the 1990 National Post-Polio Survey, between 70% and 96% of respondents with fatigue reported difficulty with concentration, focusing attention, mind wandering, memory, thinking clearly and word-finding, with 77% percent reporting moderate to severe difficulty with these problems (6)*. Of these cognitive symptoms, word finding difficulty was least expected. Of all polio survivors surveyed, 79% reported difficulty "thinking of words I want to say," with 37% reporting frequent, moderate to severe word finding difficulty (6)*. Further, the frequency and severity of word finding difficulty were significantly correlated with all of the other subjective cognitive difficulties listed above.

We studied 33 polio survivors and administered the Post-Polio Fatigue Questionnaire, Animal Naming and FAS Tests, plus tests of attention and information processing speed. Plasma prolactin was also measured as a marker for brain dopamine secretion since, as prolactin increases in the brain, dopamine decreases:

- 1) Subjects reporting high fatigue severity and word finding difficulty had clinically abnormal or significantly lower Animal Naming Test scores as compared to subjects with low symptom severity;
- 2) Impaired performance on the most difficult tests of attention and information processing speed were also associated with lower scores on the word finding tests;
- 3) A significant inverse relationship between Animal Naming Test scores and plasma prolactin suggests that a reduction in brain dopamine secretion is related to reduced animal naming ability. These data support the hypothesis that decreased dopamine secretion, possibly secondary to poliovirus damage to the basal ganglia, may underlie not only fatigue and impaired attention but also word finding difficulty in polio survivors.

Clinically, polio survivors report a "tip-of-the-tongue" phenomenon characterized by difficulty naming familiar objects and people (sometimes even family members), difficulty that increases as fatigue worsens. This complaint is similar to that in Parkinson's disease patients, who also report "tip-of-the-tongue" word finding difficulty well as "excessive" and sometimes disabling fatigue (7-9). Parkinson's patients and polio survivors are similar in that both have damage to the basal ganglia and dopamine producing neurons (6,10-12)*.

In a previous study, we found that slowing of right hemisphere electroencephalographic (EEG) activity in polio survivors, an indicator of decreased cortical activation, was significantly positively correlated with both daily fatigue severity and plasma prolactin, which were themselves significantly positively correlated (13). The association between word finding difficulty, subjective and measured impairment of attention and cognitive difficulties with "brain fatigue" supports the hypothesis that symptoms of post-polio brain fatigue are related to a decrease in dopamine release, causing a decrease in brain activation, and are not symptoms dementia (6,12-15)*.

*Published in its entirety: Cf. American Journal of Physical Medicine and Rehabilitation, 2000; 79:343-348 and with all References included –

Many polio survivors feel that health professionals are unprepared to treat them and carry with them a level of distrust. Because of passage of time, it is unreasonable to lament that my physician “never saw the original polio.” Asserting, “post-polio is never taught in medical school” is counterproductive. Medical schools teach about the acute polio infection and that it results in residual weakness. In the past, health professionals thought that polio weakness was static or stable, but most professionals today know from research and observation that it can be slowly progressive.

Many physicians are aware that there can be new weakness, but they have not seen it in many of their patients. In fact, many have never treated a person who had polio, which is why PHI makes resource materials readily available to both health professionals and lay people.

While some of the lay post-polio literature emphasizes the uniqueness of the medical problems of polio survivors, it may be overemphasized. The advice and procedures for treating common medical problems for those who did not have polio are the same for post-polio people. However, it is important to advise medical professionals that your loved one had polio (a neuromuscular disease), so they can integrate this knowledge into a treatment plan. If your parent or friend has a “post-polio physician” or a pulmonologist, who monitors their breathing status, always seek advice from them when facing other medical issues. Families are encouraged to facilitate actively the connections between the medical specialists involved in the care of polio survivors. Start with the family physician.

Family Physician

Health care reform is leaning towards the coordinated care model. A primary care health provider (nurse practitioner, physician’s assistant, family medicine doctor or internal medicine doctor) most likely will be the coordinator of your loved one’s health care. Getting to know a primary care health provider, and them getting to know your parent or friend as a person as well as a patient, can be very valuable and assures prompt appointments in an emergency. Established patients generally have priority over unknown patients when the schedule is busy.

Primary care physicians perform certain technical procedures, determine what is wrong, and offer reassurance, after an annual physical, that many things are very right. They also provide advice on how to take care of problems or to stay healthy. Not all primary care physicians know about polio or post-polio. Some are willing to learn and some are not.

Value a physician who says, “I do not know” and who gets out the books or gets on the phone and asks someone else. A physician who says they know it all is one to avoid. (At least 50 different high blood pressure medicines, about 100 different antibiotics, and 40 different birth control pills are now available.) Most primary care physicians schedule a patient every 10 to 20 minutes. Schedule more time if there are many issues to discuss. Many now have at least one exam table that goes up and down. Advise them if your loved one will need it, so they can schedule it. Write down questions and concerns. Don’t save the most important issues for the end. It is also helpful to bring a list of medicines and dosages. Take in medicines. Take in the facts. It is also useful for the primary care physician to know the number and type of orthopedic surgeries and the respiratory history, i.e., in an iron lung during the acute phase of poliomyelitis, use a bi-level device at night, etc. Some primary care physicians return phone calls and will most likely continue to do so, if they know that you will respect their time and keep the conversation short.

Health Care Specialists

There is no official certification for a “polio doctor.” The most common use of this informal designation is a physician with knowledge, experience and interest in evaluation and treatment of polio survivors.

Given the most common new disabling medical problems of polio survivors, physicians with expertise in neuromuscular disease management that includes the ability to recognize and treat chronic musculoskeletal pain and respiratory problems are ideal. The specialty background of these physicians is most commonly neurology, physical medicine and rehabilitation, orthopedics and family practice. Polio survivors do not need to see a “polio doctor” to receive good care. However, if your loved one is experiencing a series of new unexplainable and disabling symptoms and is unable to obtain satisfactory help, then seeking an evaluation by a polio doctor/ post-polio clinic can be very helpful. These physicians most commonly will provide consultation services to your parent’s primary care physician and may provide continuing comprehensive follow-up of post-polio related problems. Many survivors need a network of medical providers (orthopedist, pulmonologist, orthotist, physiatrist, neurologist, etc.) and may need help with coordination and communication among them. A primary care physician can fill this role, although many polio survivors do this function themselves, because they are sufficiently sophisticated with medical and rehabilitative issues. You as a family member may need to assume this role at certain times. The best way to frame the issue is this. Are current providers meeting the medical and rehabilitative needs of your loved one? If they are not, then specialist consultations are appropriate. If they need a comprehensive evaluation of medical concerns and functional changes, then seeing a ‘polio doctor’ is invaluable.

Here is a list, in alphabetical order, of specialists who may be involved in post-polio care.

Behavioral health specialists are psychologists, social workers, licensed counselors, marriage and family therapists, or even members of the clergy. All behavioral health specialists know about depression, anxiety and coping with life changes. Some have a special interest in working with the elderly, people with disabilities, and/or trauma survivors. Rehabilitation psychologists and counselors and geropsychologists are examples of specialists in the first two areas.

Geriatricians have special training in treating the elderly. They focus on improving the health, independence and quality of life of older people. There are 6,400 “geriatric specialist physicians” practicing in the US, and they may be hard to find, but the field of geriatrics includes not only physicians, but physicians’ assistants, registered nurses, nurse practitioners and long-term care nurses.

Medical Social Workers (MSWs) provide psychosocial support to individuals, families or vulnerable populations so they can cope with chronic, acute or terminal illnesses. They also advise family caregivers, counsel patients and help plan for patients’ needs after discharge from hospitals. They may arrange for at-home services, such as meals on-wheels or home care.

Neurologists are physicians who diagnose and treat disorders of the nervous system. They address diseases of the spinal cord, nerves and muscles that affect the operation of the nervous system. An important aspect of a neurologist’s daily duties is to offer advice to other physicians on how to treat neurological problems.

Occupational Therapists (OTs) enable people to live life to its fullest by helping them promote health and prevent – or live better with – illness, injury or disability. OTs work in hospitals, skilled nursing facilities and other places that treat people who are aging, and in rehabilitation centers and health and wellness facilities. They assess how a person accomplishes tasks and suggest better ways. Such tasks include getting on and off the toilet, in and out of a car, chair or bed, swallowing and driving, etc. Orthopedists are physicians who specialize in the diagnosis and treatment of disorders of the bones, ligaments, tendons and joints. Setting broken bones, repairing and replacing joints (such as knees and hips), straightening spines and developing prosthetics to replace body parts are specialized skills of this specialty.

Orthotists (a.k.a. certified orthotist – CO; certified prosthetist and orthotist – CPO; certified prosthetist – CP) evaluate and treat musculoskeletal disorders by designing and fitting custom-made orthoses or braces. Orthotists work to restore mobility and prevent or limit disability. Be aware that no one specialty “owns” bracing anymore and many specialties get very little training in prescribing braces. However, bracing is always included in the training of physiatrists. Check with the insurance company to see which medical specialty needs to write the prescription.

Physiatrists or physical medicine and rehabilitation (PM&R) specialists, are physicians who are experts at diagnosing and treating pain and at maximizing function lost from injury, illness or disabling conditions

through provision of non-surgical treatments and coordinating a team approach with other physicians and rehabilitation professionals. They treat the whole person and focus on not only treatment but also on prevention.

Physical Therapists (PTs) help improve movement and alleviate pain as an alternative to surgery or pain medications. PTs also treat new weakness and loss of mobility for tasks such as walking, climbing stairs and transferring. They teach patients how to prevent or manage a health condition, and are uniquely qualified to help design appropriate fitness programs to promote health and wellness. Physical therapists provide care for people in a variety of settings, including hospitals, private practices, outpatient clinics, home health agencies, schools, sports and fitness facilities, work settings and nursing homes.

Pulmonologists are physicians who specialize in the diagnosis and treatment of diseases and disorders of the lungs and respiratory system. Because of the variety of clinical problems encountered, they have knowledge of internal medicine. They are also known as respiratory physicians and respirologists. **Respiratory therapists** (RTs) work to evaluate, treat and care for people with breathing disorders. Most respiratory therapists work in hospitals where they perform intensive care, critical care and neonatal procedures. An increasing number of respiratory therapists work in skilled nursing facilities, physicians' offices, home health agencies, specialized care hospitals, medical equipment supply companies and patients' homes.

Speech and Language Pathologists (CCC-SLP), sometimes called speech therapists, assess, diagnose, treat and help to prevent disorders related to speech, language, cognitive-communication, voice, swallowing and fluency. Speech-language pathologists use special instruments and tests to analyze and diagnose the nature and extent of the problems.

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William M. DeMayo, MD.

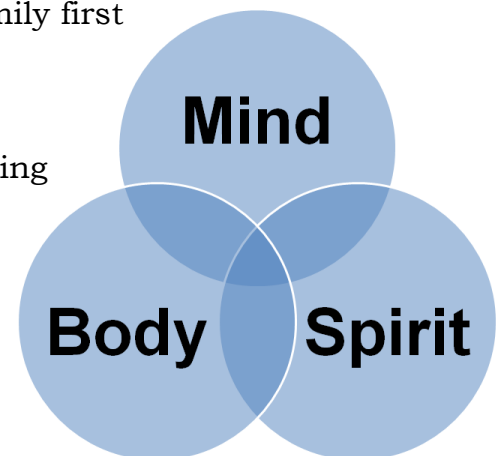
[DeMayo's Q&A Clinic](#)

"Winter Wellness" begins with "Deciding what you really **Want** to do and holding off of the things that you want to do (w = impulse or desire, but not a decision)." I believe that words that we use in our head have power over us and so deciding what we **Want** vs what we want can be an important factor in changing our decisions. Many people do this already with their finances and purchases but have not thought to apply the same language to their activity and health. Another set of similar words that can have power in influencing our behavior and health include: "**n**eed to", "**h**ave to", and "**s**hould".

The holidays are a particularly difficult time when it comes to these activity decisions. In order to avoid chronic overuse activities, some helpful questions to consider this holiday season may include:

- Do I want to continue to push myself to prepare the big family dinner (and risk creating pain and exhaustion) or do I **Want** to put my relationships with family first and preserve my energy by asking for help?
- Do I **n**eed to climb that ladder to put up decorations despite the obvious risk?
- Do I **h**ave to bake 12 dozen cookies or do I **Want** to avoid overdoing it and dial it back a bit and ask for help?
- Should "shop 'til I drop" or do I **Want** to be a better example to my kids and grandkids by purchasing or even making one special gift.

All these questions center around individual values, desires, and goals. It is my hope, especially during this holiday season, that we can all focus on our real Wants and be less driven by passing desires/wants, "have to", "need to", and a "should" mentality. The holistic model of wellness applies to us all, especially during the holidays.



**Sometimes we just have to laugh.
Happy Holidays everyone.**

**What kind of bird can write?
A pen-guin**

**What do you get if you cross Santa with a detective?
Santa Clues!**

**Why did they let the turkey join the band?
Because he had the drum sticks.**

**What do you when if you cross an apple with a Christmas tree?
A pineapple.**



**Are You Interested in the latest information
about the efforts to eradicate Polio?**

We have two outstanding videos from the World Health Organization on the “Vaccine” page of our [website](#).



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



DECEMBER



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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