



The Polio Post

Ohio Polio Network Newsletter

Editor: Alice Sporar

Spring 2011 Issue

Pat Kelly's Message

By the time you read this, Spring will have finally arrived! I know that I said this last year, but this winter has been bad. It seems like it has been snowing most of the time and I heard a forecast that we will have a cold Spring as well.

OPN's goal is to provide you with news about post-polio. We do this through the newsletter and the website www.ohiopolionetwork.org If you would like to be notified when there are updates to the website, please select "Contact Us/Request Information" from the menu and fill in the information on the form. We also encourage Letters to the Editor of the newsletter.

There are many advantages in having access to the Internet. In addition to the OPN website, you can access numerous websites devoted to Post-Polio. Consider browsing the Post-Polio International website, www.post-polio.org . Enter some keywords in the space provided for searching and click "find", for example "Cold Feet". This will bring up a number of references to cold feet. From there you can bring up the first article and skim through the information to determine if it is pertinent to your search. If not, click the back button and bring up the next reference, and so on. A new feature provided by Post-Polio Health International (PHI) is Polio Place, www.polioplace.org . This is an excellent source of information. The website is intended to allow you to "Explore the Past, the Present, and help build a Promising Future for the World's Polio Survivors". PHI is also inviting you to send "Essays" about your polio experience for consideration to be added to Polio Place. See examples at the website. Contact director@post-polio.org if you have questions.

We are excited about the interest in the formation of a new Ohio Post-Polio Support Group in Columbus. The OPN Board will assist in the formation of the group at the meeting at the Westerville Library on April 16th. The OPN Board Meeting will be from 12:00 -1:30 PM followed by the Columbus Post-Polio Support Group Organizational Meeting from 1:30 -3:00 PM.

On behalf of the OPN Board, I would like to wish each of you and your families a wonderful spring and Easter.



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2010 Ohio Polio Conference

Dr. William DeMayo, Best Practices in Medical Care: Implications For Polio Survivors

By Warren and Judith Peascoe

Dr William DeMayo, Medical Director Neuroscience Specialty Clinic at the JP Murtha Neuroscience & Pain Institute in Johnstown, PA was the primary speaker of the Ohio Polio Conference.

Dr DeMayo started by reading a poem, *Second Best*, written by a Jude King, a polio survivor, that he felt very moving. The poem was published in the last newsletter and is also posted on the Ohio Polio Network website, www.ohiopolionetwork.org

He gave an overview of the John P. Murtha Neuroscience and Pain Institute facility, program, and support services. The clinic does a comprehensive evaluation using physiatrist, nursing, orthotist, and as needed occupational therapy, physical therapy, nutrition, speech and language pathology and respiratory therapy. (They have three people with computer chips in their braces)

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OPN Board Meeting

Saturday, April 16, 2011

Westerville, OH Library

Board Meeting Noon - 1:30 PM

Columbus Post-Polio Support Group Organizational Meeting

1:30 - 3:00 PM

OPN members are welcome to attend. OPN is always looking for members interested in becoming Board Members. If you are interested or have agenda items for the Board Meeting, please contact Patrick Kelly, pkelly03@sprynet.com

Dr. DeMayo continued from page 2

“Best Practices in rehabilitation medicine” was defined as comprehensive, individualized, holistic, goal oriented with functional outcomes, and patient centered. The patient has to set goals. The “polio personality” has to be considered in treatment to distinguish between the effects of polio and other conditions,

Dr. DeMayo focuses on education and self-management. Individualized exercise can address pain and physical impairments. Medical management of inflammatory conditions and pain along with customized recommendations on bracing can achieve specific functional goals. The facility blends traditional medicine with complementary healing methods like aroma therapy, massage, Yoga, and WASU. He supports complementary medicine but not alternative medicine.

Holistic support of wellness applies to all of us. Mind--Body--Spirit . Important considerations include: family and support groups, meditation, mindfulness, humor, fun, art, gardening, pets, massage, aroma therapy, music. Part of treatment is to enable the patient to pursue what interests him.

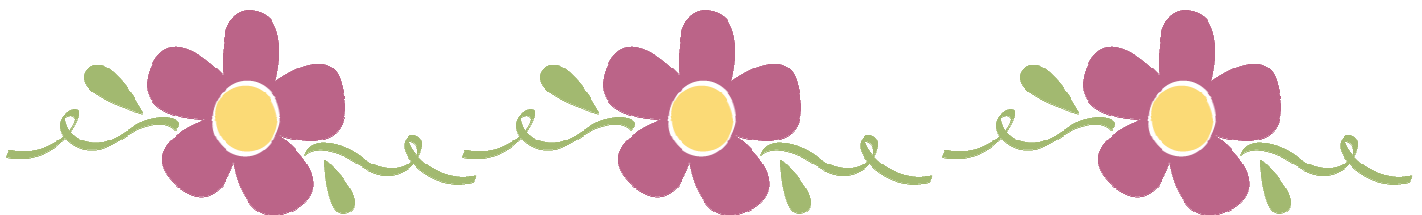
Dr. DeMayo provided a practical example of the interaction between mind, body and spirit-- This is the myofascial pain cycle which is a component of most chronic pain and can last long after the injury heals. For example, if a dog hurts his paw he will lift his leg. This is a muscle spasm caused by pain. In turn, the muscle spasm causes more pain. If you add insomnia, stress, lack of peace, and anxiety to the situation, the pain can become very intense. Imagine someone hit by a drunk driver focusing all his rage on his pain. That’s got to hurt!

Most treatment focusses on the body and ignores the mind and spirit. Body--ortho-neuro impairments lead to loss of physical function. Mind--What motivates me? Self-awareness. How can I adapt? Spiritual--Is there a God? Do prayer and meditation help?

Spiritual exercises can lead to a sense of peace and take the focus off the person. They can help clarify an individual’s relationship to God. An example was given of the book: ***It’s Not About Me*** by Max Lucado. But he felt that blind obedience to a religion could be harmful and used the Jonestown deaths as an example.

Dr. DeMayo felt we had to put things in perspective. It’s easy to focus on ourselves. Occasionally we need to think about how we fit into the community, country, planet, solar system, galaxy, universe. He showed this in a wonderful series of slides going from a slide of people to a slide from the Hubble telescope showing distant galaxies. He then asked the question, “Now how big are you and how big are the things upsetting you?”

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Dr. DeMayo continued from page 3

Goals to aging well with post polio include health issues like maintaining weight, balanced nutrition, adequate sleep, healthy lifestyle habits and emotional wellbeing. The survivor needs to reduce fatigue, control pain, and maintain self-care abilities and mobility. To attain these goals he must be aware of home safety and prevent falls. Dr. DeMayo quoted “failing to plan is planning to fail” and “if you set your goals on nothing you’ll hit it every time”.

Dr DeMayo mentioned a program developed at Stanford and published in the book, ***Living a Healthy Life with Chronic Conditions Self-Management of Heart Disease, Arthritis, Diabetes, Asthma, Bronchitis, Emphysema and others*** by Kate Lorig, RN, DrPH, Halsted Holman, MD, David Sobel, MD, Diana Laurent, MPH, Virginia Gonzalez, MPH, and Marian Minor, RPT, PhD. The J P Murtha Institute had trained some people to train others in this method.

When Dr DeMayo discussed pain, he said that secondary factors often need to be addressed before the primary pain generator can be modified. He described this as like shutting off the gas before putting out the fire. Behavioral issues can put us into overdrive and lead to sleep issues. Therefore, we need to learn stress management before we can effectively deal with our pain.

We need to rephrase our thoughts. Avoid “I can’t” and use “I don’t know how to--- or it’s difficult for me to--” Avoid “I need to--, I have to --- or I should” and use “I want to ---” “I can’t” and “I need to” imply that we have no responsibility and close the discussion. “I don’t know how” and “I want to” open the discussion and show that we are looking for help.

It’s essential to take responsibility for choices in order to establish a plan for pacing activity and minimizing effects of overused muscles. A patient makes choices, but may not like consequences. It is easier to focus on doing the lesser evil than going to the next step. Dr. DeMayo discusses possible treatments such as 1) doing exercises, 2) taking drugs or 3) a medical procedure. His hope is that a patient, who does not want to use drugs or have a medical procedure, will decide to do his exercises. (To prevent what is likely to develop next is a strong motivation for what can be done now)

Behavioral issues are important in chronic pain management. Dr. DeMayo used the following as a conceptual approach to preventing overuse injury. On the activity scale, we are all between the couch potato and the ultra marathoner. All of us have a definite capacity on a given day. Inactivity, increasing age and over activity will move us toward couch potato status. Appropriate daily exercise and activity will move us toward the marathoner. The optimal level of activity is just below capacity. To test our capacity we need to occasionally step over the capacity line in a planned and anticipated manner. It should not be because “I have to--” or “I need to--” which puts pressure on us. Pressure to overdo comes from within us and from others. The worst thing we can do is to severely over use our muscles and then collapse and then get into an “over use / collapse” cycle. This lowers capacity and forces us toward the couch potato status.

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Dr. DeMayo continued from page 4

Sleep disorders can be obstructive sleep apnea, periodic leg movements, and hypoventilation. Treatment includes sleep positioning (Dr. DeMayo recommended a body pillow) and sleep hygiene and stress management. Sleep hygiene includes a disciplined schedule, avoiding stimulation and distraction and active peaceful relaxation. Lack of sleep causes reduced ability to cope with pain, exacerbates neuropathic pain, and feeds into muscular spasm. Stress will also lead to the above.

An example is a man who slept for only two hours. He had lost his job, was getting a divorce, and in a custody fight over children. To maintain his spiritual health, he walked in woods and talked to God each day. The treatment was to do the same thing (or think the same thoughts) before going to sleep. When implemented he was able to sleep for 5 hours.

Medical management (drugs) for stress can be counter productive. Complementary techniques can help--Yoga, tai-chi, aroma therapy, acupuncture, massage, aquatics, WASU.

Dr. DeMayo used frustration in an example of Cognitive Behavioral Therapy. Frustration is stress caused by not meeting your expectations. There are three options: 1) Continue to be frustrated. 2) Work harder and smarter to meet expectations. or 3) Change expectation. Changing expectations is often where appropriate exercise, occupational and physical therapies can help.

Dr. DeMayo's final thoughts and conclusions were: If a current model is not helping, consider a new paradigm. Eliminating exacerbating factors is often a key to improvement. Take responsibility.

2010 Ohio Polio Conference

Janet Goodard BSN, RN, CCRC, CCAP

Research Opportunities for Polio Survivors

By Warren and Judith Peascoe

Janet Goodard opened her presentation by describing how to obtain information about research trials and the research subject's rights. A patient should only participate in studies that fully comply with those rights.

If you are interested in participating in a research trial, she suggested looking for one at Post Polio Health International <http://www.post-polio.org> under the research tab <http://clinicaltrials.gov> or search for polio or post-polio syndrome.

Janet Goodard urged anyone taking part in a study to know his rights and to be sure the study is complying with those rights. Research subject's rights include:

- Knowledge of why the study is being done
- Information about procedures, actions, drugs or devices
- Information on any discomforts or risks

Continued, see Goodard on page 6

PPS FATIGUE: HOW IT CAN CHANGE YOUR MIND

Mavis J. Matheson, MD

One of the most frustrating late effects of polio for me was the awareness that I could not concentrate and a feeling that I wasn't thinking clearly anymore. For many of us who have compensated for our physical limitations through intellectual pursuits, this is a terrifying feeling. . Is it not bad enough that our bodies are giving out? Must we undergo the indignity of losing our minds as well? Studies show that in spite of marked impairments of attention, polio survivors are within the high normal or superior range on measures of higher-level cognitive processes and IQ.

Continued, see PPS Fatigue on page 7



Goodard continued from page 5

- Information about any benefits or value to expect from the study
- The right to be free of pressure to consent to the study
- The right to quit the study at any time
- The right to consent or not to consent to be in a study
- The right to ask questions about the study or the procedures
- The right to have a copy of the signed and dated written consent form

Janet Goodard urged post polio survivors to register with the John P. Murtha Neuroscience and Pain Institute registry of polio survivors which provides a description of survivors based on demographics. It is used to identify trends in polio history, PPS and interventions and to develop future clinical research studies. The registry can be found on line at <https://www.postpolio.conemaugh.org> or by phoning 1-800-707-8424 for a paper copy. The registry is currently being used to obtain a picture of the age distribution of the survivors. Those who have registered are younger than estimated.

Janet Goodard went on to describe ongoing and past research projects carried out at the Institute. Their current research is on sleep apnea using a portable home monitor. They are still recruiting. A subject must make 3 visits to Johnston. If you are interested call Wendi Nagle at 1-866-707-8424 (email wnagle@conemaugh.org) or Janet Goddard at 814-269-5288 (email jgoodar@conemaugh.org)

They had an educational retreat using Hatha Yoga in 2003. It was a five day retreat with 12 weeks of home practice using a video. There were 23 participants. People who wore braces or used wheelchairs were excluded.

They participated in PPS Wellness Retreat (2006, 2007) at Bay Cliff Camp, MI run by Dr. Maynard. She was not sure if it has been offered after the Wellness retreat at Warm Springs in 2010.

2010 Ohio Polio Conference

Lee Owen, Mobility Consultant for the Rascal Company

Presentation on Wheelchairs/Scooters and Medicare

By Warren and Judith Peascoe

Lee Owen talked about the process of obtaining equipment through Medicare and recent rule changes.

Medicare wants to keep people out of nursing homes at minimal expense. The program moves people needing mobility assistance from a cane to a walker to a manual wheelchair to a power operated vehicle (POV). To obtain equipment the patient needs a doctor to do a mobility evaluation and write a prescription. The doctor has to put the most severe ICD9 (code for medical conditions) that he can justify without exaggerating. The process of obtaining Medicare approval is a four to six week process (from experience he felt he could shorten the application procedure)

Lee Owen explained that there are new rules under Medicare. Medicare used to replace same or similar equipment every 5 years--now it is every 7 years and this is retroactive. Medicare will not automatically repair medical equipment but may apply income guidelines. Medicare has added the requirement that POVs are to be for use in the home so that scooters are not usually obtainable through Medicare.

Lee Owen demonstrated the operation of 3 scooters. One of the scooters was obviously made for outside use. They had magnetically locking castors to prevent them from tipping over. Two were smaller with a 19 or 22 inch turning radius. These could also either fold up or be taken apart. One could fold to be a powered walker and then unfolded to be a scooter. One powered wheelchair was 23 inches wide. This size is narrow enough to be used in a single-wide trailer. The chair had no headlights and no basket and was for inside use only.

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They also show that if we allow ourselves to become fatigued, we do lose our ability to focus our attention and to rapidly process complex information, requiring 23 to 67 percent more time to complete tasks requiring sustained attention and vigilance than did polio survivors with no fatigue or mild fatigue.

Polio survivors experience two kinds of fatigue. One is physical tiredness and decreased endurance. The other and often more distressing kind is "brain fatigue." Brain fatigue describes problems with attention, alertness and thinking. Between 70% and 96% of polio survivors reporting fatigue complained of problems with concentration (96%), memory (85%), attention (82%), word finding (80%), staying awake, and thinking clearly (70%). Tests indicate that an impairment of selective attention, related to damage as a result of polio, results in feelings of fatigue and cognitive problems.

The polio virus damages the anterior horn cells of the spinal cord, but that is not all it damages. It also damages parts of the brain stem. *Continued, see PPS Fatigue on page 8*

PPS Fatigue continued from page 7

Findings indicate that the polio virus consistently and often severely damages the brain areas known as the reticular activating system. These areas are responsible for activating the part of the brain involved in maintaining voluntary attention, memory, spontaneous interest, initiative and the capacity for effort and work, and for preventing feelings of fatigue. This is the area that keeps us awake and allows us to focus our attention.

Polio survivors report that they are most disabled by the visceral symptoms of fatigue. These are feelings of exhaustion, passivity, and an aversion to continued effort, that generate an avoidance of both mental and physical activity. Dr. R. L. Bruno suggests the existence of a fatigue generator in the brain. His findings suggest that there is a close relationship between impaired attention and fatigue. There would be survival value in a brain mechanism that promotes rest when attention and information processing ability are impaired. An area of the brain, the basal ganglia, may generate mental and physical fatigue. When the reticular activating system is damaged, the fatigue generator takes over and produces problems with focusing attention and with physically moving without significant conscious effort. Damage caused by the polio virus chronically reduces the firing of the nerve cells in the reticular activating system. Rest or sleep would increase the firing of the brain activating system nerves, restore activation and once again allow motor behavior.

The damage would explain why polio survivors have difficulty concentrating after the original infection, but why are we developing problems thirty or forty years later? One theory is that the age-related loss of nerve cells combined with an already abnormally small number of nerve cells as a result of the original polio virus infection may impair the brain's activating system enough to produce impaired attention and fatigue as polio survivors reach mid-life.

The first step in treating the disorders of concentration, memory, attention, word finding, staying awake, and thinking clearly, is to deal with the fatigue. Energy conservation, work simplification and the proper provision of rest periods throughout the day are the treatments of choice in dealing with post-polio fatigue. Stress management is also critical in the treatment of post-polio fatigue. Dr. Bruno et al are currently studying the use of a medication, a post-synaptic dopamine receptor antagonist currently used in the treatment of Parkinson's Disease, in the treatment of post-polio individuals who do not respond to conservative treatments. They caution that there is a real danger that treatment with medications will allow polio survivors to resume their hyperactive type A lifestyles and further stress polio virus damaged "metabolically vulnerable" neurons in the brain stem and anterior horn.

As with any treatment strategy, we must try to find the most effective treatment that will do the least long-term damage while helping us to deal with our current problems. Certainly, reducing physical and emotional stresses in our lives and getting adequate rest makes sense for everyone, even polio survivors. The good news is, if you can get rested, you will find your ability to concentrate, pay attention, remember words, and stay awake will improve. You may even find that you can enjoy reading and thinking again!

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