

Newsletter

SEPT 2013

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SWITCH OF SPT. AND NOV. SPEAKERS

There has been a shift in our meeting schedule for the months of September and November. The HICAP meeting originally scheduled for September has been moved to November to accommodate the schedule of Dr. Donna Barras of Rancho Los Amigos. Dr. Barras, a colleague and contemporary of Dr. Jacqueline Perry will be at Villa Park to speak to the Orange County group and anyone else who wishes to hear her or ask questions. Dr. Barras is also a polio survivor who looks at the disease from the same perspective shared by many of us. That affords her a view that differs from other physicians who may not have that same experience.

In November, we will once again be offered an overview of the choices

available to us in healthcare plans. If you are one of the many people who have individual plans that may be being discontinued on December 31 of this year and are looking at the options within the many plans being provided under the Affordable Care Act, this will provide an opportunity to get the information you need to make a knowledgeable and cost effective choice.

Join us at the Villa Park City Hall on the second Saturday of each of these two months at 2:00 in the afternoon.

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MEET OUR MEMBER

CECELIA MAY

Cecilia Wiant May

Born in Beijing, China, while her parents were professors at Beijing University, Cecilia Wiant was 2 ½ years old when she contracted polio. She received her early polio treatment at Peking Union Medical College, an enormous 22 building medical center built by Rockefeller Foundation money. Her mother provided physical therapy and massage taught to her by Mary McMillan, who helped establish the American Physiotherapy Association in the United States and happened to be working as a physical therapist in China. Cecilia affectionately knew Mary as "Aunt Molly" and she and Cecilia developed a

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special bond. When Cecelia married years later, one of the first things she did was introduce her new husband to her beloved "Aunt Molly".

In 1935, when Cecilia was 4 years old, her family returned to the U.S. and traveled to Boston for medical treatment for her polio. Her physician, Dr. Brackett, was also a polio survivor, and when Cecilia's parents tried to pay for her treatment, they were told that Cecilia had already paid for her treatment by entertaining him with some Chinese songs and he refused any other payment. While she was in the United States, Cecilia improved her English language skills, as her original language was Mandarin (one of the many dialects of the Chinese language) taught to her by the woman who cared for her while her parents worked. Prior to returning to China, she spent a summer at a hospital in Elyria, Ohio for polio treatment. Her parents and family were not allowed to visit or see her and she remembers that was a very lonely and sad time for her as a 4 year-old girl. At the end of the summer, she was reunited with her parents and three brothers and the family returned to China where they would stay until January 1941.

After the war, the family returned to their home in Beijing and in 1949, Cecilia graduated from the Peking American School. After graduation, Cecilia studied for a year at Peking University and lived in the dormitory. She roomed with 2 girls, one spoke the dialect from Canton and one spoke the dialect from Shanghai. After hearing her talk in her sleep one night, her roommates asked her to teach them Mandarin. She was proud to do so.

When her freshman year at Beijing University ended, Cecilia came back to the United States to study at Whittier College, a campus she chose both for its mild California climate and the fact that her father had been a Methodist Minister and received a tuition discount. While attending Whittier College, she worked at the Campus Inn and dormed at Bolte Hall. The many hills and slopes of the college challenged Cecilia as she made the climb several times a day with a leg brace.

After receiving a bachelor's degree, she accepted an internship for one year to complete her training as a registered dietician at Christ Hospital in Cincinnati. At that time, all of the interns were required to also spend part of their internship at Children's Hospital. Cecilia walked great distances between there and Christ Hospital along Cincinnati's hilly streets, another difficult physical challenge. While doing her internship work at Children's Hospital in Cincinnati, she decided that working with children is what she wanted to do. After completing her internship, she accepted a job at Children's Hospital in Columbus, Ohio (even though it paid less than positions she was offered elsewhere) so that she could be closer to her family that lived in Delaware, Ohio. During her employment at Children's Hospital in Columbus, Cecilia obtained a master's degree from Ohio State that eventually led to a position at Ohio State University Hospital.

Life happens, and in the midst of accomplishing all of these things, Cecilia met the love of her life, her husband Michael May. "He knew about my disability and he accepted me and has been a wonderful husband." They married in Columbus, Ohio and all three of their children were born

there. When the family was still young, her husband's job brought them to California and they settled in Tustin. In December, they will celebrate 56 years of marriage. In addition to their children, they have three beautiful teenage granddaughters.

Today, Cecilia wears a brace on both of her legs and chooses to use a wheelchair to prevent falls. She sings in the choir at Aldersgate United Methodist Church in Tustin, CA. Cecilia is grateful that one of her fellow choir members was kind enough to build an extension so she could roll her wheelchair up and sing in the front row of the choir loft.

Recently, Cecilia's entire family vacationed in Hawaii. While there, Cecilia and Michael took a ride of a lifetime in a helicopter to see the beautiful tropical scenery from a whole different perspective. When asked if the family took this trip to celebrate something special, Cecilia replied, "just to celebrate being together." Life doesn't get any better or more special than that.

If you are interested in sharing your story, please contact Debbie Hardy, PPS Story Editor, at (562) 693-6265.

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From Post-Polio Health, Vol. 26, No. 1, Winter, 2010:

Aging Well with Post-Polio Syndrome: Dealing with Pain

Chronic pain is something that many people, including many individuals with post-polio syndrome (PPS), face on a day-to-day basis. In fact, from the preliminary results of our recent survey of post-polio people, we found that 373 out of 419, or 89 percent, reported at least some daily pain. Of these individuals, more than half (227) rated their

average pain as being equal to or greater than five on a scale of one to 10. While it is of little comfort to those experiencing PPS, you are not alone!

Although these results are preliminary, we previously completed a survey with a smaller number of participants (63) with post-polio syndrome. In this study we also found that pain was a very common issue for people experiencing PPS. Some 91 percent of the survey participants reported pain, and everyone who experienced pain also reported that they had not been pain-free during the previous month.

Another sign that pain is a major issue for people with PPS is that, in our surveys, those who reported pain said that they have experienced pain for an average of 20 years. We also asked people about where they experience pain most frequently. People responded that they most frequently felt pain in the shoulders, lower back, legs and hips. Pain intensity was greatest in the knees, legs, wrists, lower back and head. Knowing where the most common and most severe types of pain occur is a good start to finding ways to help reduce that pain..

Another problem with pain, and why it needs to be addressed, is that it often interferes with activities that are important to people. We also asked about this in our smaller-sample survey, and found that pain interfered most with sleep and with recreational activities, mobility and normal work activities, in that order.

Finally, we found that 70 to 95 percent of those in the smaller survey had tried a number of pain treatments – heat, acetaminophen, ice, aspirin or ibu-profen, strengthening exercises – but fewer than

half of the participants with pain were using any pain treatment at the time of the survey.

The next step is to investigate ways to reduce the interference of pain in important daily activities and to test what is most effective in reducing pain for most people. It's also important to understand which coping methods are both effective and easy to use, so that people can incorporate them into their lives and continue to use them to treat their pain.

The amount of pain that people with PPS report may not surprise anyone experiencing PPS, but this is critical information to support further research about PPS pain. From such research we can determine which areas of pain are most important to target, and re-searchers can begin to design and test interventions to reduce the degree to which pain interferes with key activities. In future columns, we'll discuss research findings regarding different treatment options for pain management.

The contents of this column were developed under a grant from the U.S. Department of Education. However, the contents do not necessarily represent the policy of the DoE, and endorsement by the federal government should not be assumed. ###

Every Body Benefits from Massage

Leslie Drawdy, PT, DPT, CLT-LANA, Tucson, Arizona, lesliedrawdy@gmail.com

Massage is known to have many general health benefits, including decreased stress and anxiety, increased blood flow, decreased blood pressure, decreased pain and stiffness. Certain techniques can also result in decreased edema and hypersensitivity. Many people with post-polio syndrome (PPS) suffer from pain, cold intolerance and hypersensitivity. Most research and books on PPS management simply state that massage may be helpful in managing these symptoms; however the medical literature lacks more specific information.

Traditionally, deep tissue massage or Swedish massage are the methods of choice for improving blood flow, decreasing muscle spasm and promoting muscle relaxation. However these techniques can produce pain for several days afterward. This can cause decreased function for certain individuals with PPS while the muscles are recovering. Other techniques can be just as effective.

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For example, the strain counter-strain (SCS) method of manual therapy is often very effective, and easily taught to a patient and/or spouse/partner. Although it sounds painful and aggressive, it is actually quite the opposite. The therapist places the limb in the most relaxed position to mechanically reduce the stress on the muscles in question, and then uses light manual pressure specifically at the sites of spasm or palpable soft tissue abnormality to get the muscle to relax. This type of therapy actually retrains the muscle and can have a long lasting effect.

Physical therapists, occupational therapists and massage therapists all use massage for different purposes in their practice. Massage therapists are certainly the experts in different massage techniques and are able to devote their time to relaxing the whole body. They can concentrate more of their efforts on the body part you request them to, but they are also able to address all the muscle groups and improve the whole body fluid flow.

Physical and occupational therapists use specific soft tissue mobilization techniques to promote pain relief and improved muscle function as it relates to specific mobility issues and edema management. If you have significant amounts of ongoing pain and muscle tightness, one recommendation might be to have massage therapy to address the pain and muscle tightness, and also have physical or occupational therapy to correct the underlying mechanical problems that are causing your continued symptoms.

Massage doesn't have to be performed by a professional in order to be helpful. Generally speaking, if it feels good, it is okay. If your spouse is massaging your

legs, for instance, give him/her specific feedback about what feels good and what doesn't. It's always a good idea to start with lighter pressure, and then ask them to increase the pressure as you feel it is necessary. Massage does not have to hurt to be beneficial. For increased blood flow and muscle relaxation, moderate pressure is often very effective without producing painful side effects.

Using a heat pack prior to massage may help to relax the muscle, making the massage a little easier. The more fully the hand is in contact with the area to be massaged, the more relaxing the massage will be. Digging in with fingertips can cause stress and hand pain for the person performing the massage and can be irritating to the recipient. Applying pressure through the heel of the hand is better.

If you have a muscle spasm or trigger point, holding constant pressure to the area is the best way to relax it. This is as trigger point therapy. The mistake most people make is to dig their fingers into the area of spasm and rub back and forth. This can be very irritating and cause more pain as well as actually aggravate the spasm and cause the surrounding muscles to tense. Start lightly, and gradually increase the pressure until the trigger point relaxes. Take intermittent breaks, or alternate between areas of spasm. Once the spasm is relaxed, perform gentle, even strokes to the general area with the heel of the hand.

Although typically not as relaxing or easy to do, self-massage can still be helpful. It is important to listen to your body's feedback. Don't be too aggressive. Try to find the most relaxed position you can. You don't want to increase your pain or muscle tension in your arms and neck while massage

Massage (continued)

ing your foot! The same principles and techniques of massage with a partner apply here.

Self massage can be performed whenever you feel you need it. Many of my clients initially perform home massage daily, and then decrease the frequency as their pain improves. The best parameter is to listen to your body.

There are some circumstances in which massage must be performed more carefully. Limbs with chronic edema, hypersensitivity, fragile skin, open wounds, or diabetic neuropathy must be approached a little differently. Aggressive massage may be intolerable and could cause more problems. In these cases, a very light technique is helpful. It can be relaxing and pain relieving and may even be helpful with edema management..

The best technique in these situations is one similar to the Manual Lymph Drainage technique used for lymphedema patients. Starting at the top of the affected limb, using full contact with the palm and fingers of the hand, apply enough pressure only to stretch the skin. Gently pull the skin toward the top of the limb. Then move your hand down a bit on the limb and repeat, working your way down to the end of the limb. This technique is helpful with multiple types of swelling, and has been very successful in reducing hypersensitivity. If you struggle with either of these issues, I would recommend getting a referral to a lymphedema therapist or seeing a massage therapist who is trained in lymphedema management. They can teach you and your partner exactly what to do. It is very easy to learn, but it is a little different for each person.

If the skin is very fragile or there is an open wound on the limb in question, use caution. Keep the skin well moisturized, and never apply direct pressure over the site of a wound. However very light any application of pressure, or the lymphedema technique described above can be used safely.

If you have diabetic neuropathy, you must keep in mind that your sensation is altered. You may not be able to accurately assess whether the amount of pressure during a massage is okay. Light to moderate pressure is best to avoid any soft tissue damage.

Don't be afraid to seek professional advice! If you have any concerns or struggle with any of the specific issues listed above, one or two visits with a professional for instruction on the correct massage method for you may be well worth it. S

The articles on Pain and Massage are Reprinted with the authorization of Post-Polio International and Ventilator Users Network Winter Editions of 2010 and 2011, respectively.

DEAR JR

The Dear JR column had no requests or comments for this issue. To submit questions or comments, submit them to Editor at renison@cox.net Please indicate Dear JR in the Subject. Thank you for your participation. J. Renison



Rancho Los Amigos Mitg.

Saturday, Sept 28, 2-4 PM

Medical Equipment

Future Rancho SG Meetings

Saturday, Sept. 28 2-4PM
“Academy Med. Equipment”

Orange County Meeting

Saturday, SEPT 14, 2-4 PM

Dr. Donna Barras

Future PPSG of OC Meetings

Saturday, Sept. 14, 2013 2-4 PM
Dr. Donna Barras

Saturday, Nov. 9, 2-4 PM
HICAP

Donations needed year round! Note that we mention donations but not the amount, as all donations make the OC and Rancho groups possible. Please write checks to Polio Survivors Association and write “Newsletter” in the memo section. Please mail checks to Priscilla Hiers, Treasurer PPSG of OC, 18552 Cork St. Fountain Valley, CA, 92708. There were no donations for the past two months.

Please be aware that this newsletter is made possible by donations from members and other such interested parties.

How to contact Rancho Support Group

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association

For add additional information please call Richard at 562-862-4508

Email: RanchoPPSG@hotmail.com

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Agenda ideas for PPSG of OC ????

Please call Aleta at **949-559-7102** or email Priscilla: prisofoc@aol.com

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of Orange County**

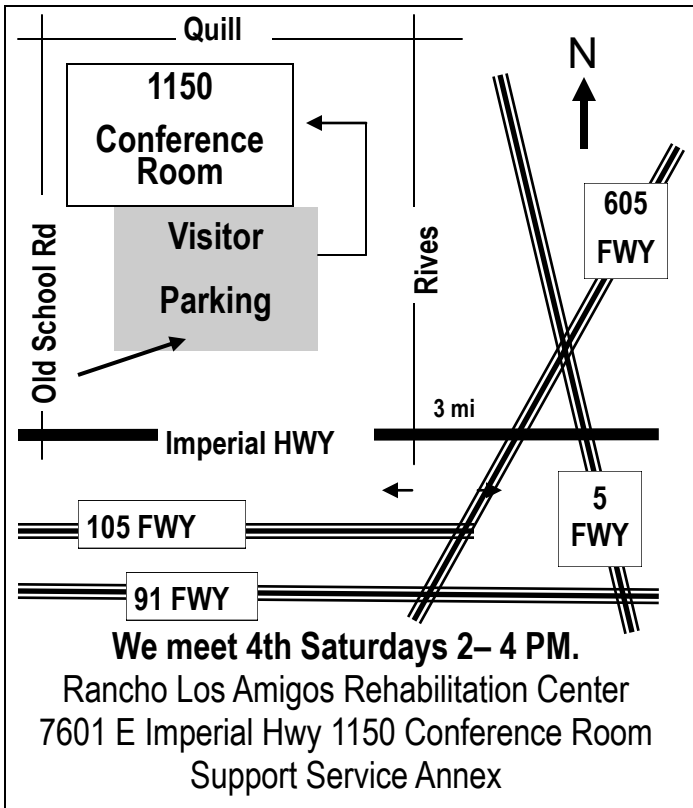
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