THE LIGHTHOUSE Coastal Empire Polio Survivors Association, Inc. Shining Light on Post-Polio Health

June, 2014 Newsletter

www.coastalempirepoliosurvivors.org

Vol. XVII, No. 6

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Next Meeting Saturday, June 28, 2014 10:30 AM at Nancy N. and J.C. Lewis Cancer and Research Pavilion Room 203

The President's Message...

A appy Summertime! Ready or not, we have to deal with high temps and high humidity in the South. Remember when the heat did not bother us, and we wanted to be outside, preferably playing in water. My sister and I tried to get suntans, even with our red/auburn hair and light,

freckled skin. No success there. Now we polio survivors do not deal well with extreme heat. Our doctors caution us to stay hydrated and cool. Yet, we cannot deal with highly air-conditioned places either. Wishing you a good summer whatever you do and wherever you are.

We were so pleased to see Dot and Bob Parkhurst at our May 17 meeting. For the program History Chair Diane Davis directed us in sorting and placing CEPSA articles, letters, and pictures into our history books. There were laughs and tears as we reviewed busy, happy times in this group. Some articles and pictures included members no longer here. Diane has done an awesome job in preserving our history. Several of us volunteered to form a committee to continue working on the books. The committee will meet several times this summer.

Polio survivors remain very concerned about the continued outbreaks of polio. As of the week of June 4, the global polio count was 89. The global count was 45 one year ago. The countries of Equatorial Guinea, Iraq, Cameroon, Syria, Ethiopia, and Somalia were not on the list in June 2013. They are this year with small numbers of new polio cases. Tragically Pakistan just had 3 more confirmed cases for a total of 71. Travel restrictions are in place in that country to prevent the spread of the disease.

Join us for our June 28 meeting, the last before our summer break. Our own Adrienne Stallworth will present a revised version of a program she presented for us several years ago. Are you ever frustrated about all the paperwork you have in your life? Which documents must be kept and how long? Do you know which documents you no longer need and now can shred? Adrienne worked at Wells Fargo prior to her retirement and advised her clients on these paperwork issues. Members gave rave reviews of her previous presentation for CEPSA.

Remember that **we will not meet in July and August**. Don't forget that we have a summer luncheon planned for August 2, Dutch treat. Join us for lunch as we celebrate Miss Archie Ivey's 89th birthday with her. Your care team leader will call in late July to remind you about the luncheon.

Cheryl Brackin

Coastal Empire Polio Survivors Association, Inc.

General Meeting Minutes May 17, 2014

Location: Nancy N. & J.C. Lewis Cancer & Research Pavilion, 2nd Floor, Room 203

Call to Order/Welcome: President Cheryl Brackin called the meeting to order at 10:38am. She thanked those in attendance and particularly welcomed back Dot and Bob Parkhurst..

Pledge of Allegiance: Lorraine Frew led the Pledge of Allegiance. She also led a moment of silence in honor of Memorial Day and those whom we have lost in service to our country.

Inspiration: Wanda Clas gave the inspiration. She read the story of "The Carrot, the Egg, and the Coffee Bean." This story taught how we can each react differently when challenged with adversity.

Business Meeting:

Approval of Minutes: Minutes from the March meeting posted in our newsletter were approved as written.

Financial Report: The treasurer's report was given by Terri Dunnermann and approved as presented.

Care Team Reports: Ruth Parham is concerned about her son Wakil Carter, Sr.. Marty' Foxx's sister in-law is critically ill. Sandra's sister Cheryl Hood passed away. Concerns also were expressed about Jim Veccia, Terri Dunnermann, and Janet DiClaudio. Some reports were not available.

Old Business: Anniversary Meeting: We had wonderful speakers, and all went well. In reviewing, we need to request a better room arrangement for next year.

New Business: An open discussion was held about CEPSA participating in the Smart Living Expo and Health Fair on June 20th from 9am to 1pm at the Civic Center. The booth will cost us \$60, and we needed to vote and have volunteers to be on-site. A motion was made and approved that we participate. Cheryl will carry the display items for the table. Carlos Clas, Lavonne Calandra, and Lorraine Frew volunteered to staff the booth with her.

A discussion was held that we consider honoring Janet DiClaudio with a plaque for her dedication and service, including getting us 501(c)3 status as a non-profit organization. The proposal originally was made by Harvey Varnadoe and Tom Schendorf after their visit to Janet. A motion was made and approved to obtain a plaque and present it on June 17, Janet's birthday.

Michael displayed a transport chair donated by the

Dunnermanns's friend Gloria West to be used at our functions.

The business meeting was adjourned at 11:29 pm, and we began our program of updating our history books.

Respectfully submitted, Michael Dunnermann, Secretary

Attendance: Cheryl Brackin, Wanda & Carlos Clas, Michael & Terri Dunnermann, Lavonne Calandra, Sissy Morel, Betty Goff, Lorraine Frew, Joan & Alan Page, Bob & Dot Parkhurst, Diane Davis, Tom Schendorf .

Upcoming Meeting Dates

June 28, 2014***

July & August - No Meetings August 2, 2014 - Summer Luncheon (noontime, Dutch treat at Johnny Harris Restaurant 1651 E. Victory Dr., Savannah, GA 912-354-7810) September 27, 2014 @ *** October 25, 2014 @ *** November - No Meeting December 6, 2014 @ Hilton Garden Inn

> *** (General Meetings) @ Nancy N. and J.C. Lewis Cancer & Research Pavilion, Room 203

Our June Program

"What Documents Should We Keep? Cleaning Out Our Filing Cabinets" will be presented by CEPSA member Adrienne Stallworth. She was employed at Wells Fargo prior to her retirement. Her job duties included advising her clients on which paperwork must be kept and which could be destroyed. Adrienne presented this program for us several years ago and did an excellent job. Join us June 28 to hear this practical, much-needed information.

> Voluntary Dues of \$20.00 may be paid to:

CEPSA P.O. Box 14252 Savannah, GA 31416

Please try to make your payment this month, either at our next meeting or else by mail. **Thank you.**

Come visit the CEPSA booth at the Smart Living Expo and Health Fair

Join thousands of seniors at the Coastal Empire's largest and most unique senior expo and health fair.

When: 9 A.M.-1 P.M.; Friday June 20, 2014

Where: Savannah Civic Center, 301 W. Oglethorpe Avenue. Free parking at the Civic Center. A free shuttle will be available from the Smart Senior office at 8 Medical Arts Center.

Free Health Screenings & Consultations

- Glaucoma Screenings
- Chiropractic/Spine Evaluations
- Blood Pressure Checks
- Lung Function Tests
- Osteoporosis Screening
- Sugar/Glucose Checks
- Medicare Counseling
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Other Activities & Classes:

- Exciting Travel Ideas
- Lifestyle & Housing Options
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- Volunteer Opportunities
- Jewelry Sale
- Estate Planning/Long Term Care Options
- Health Education & Support Services
- Weight Loss Products
- Line Dancing Demonstration/Class
- Free Chair Massages

Please call SmartSenior at (912)-352-4405 or visit: <<u>http://www.sjchs.org/media-center/news-story?</u> <u>news=66</u>> for more information.

Every Body Benefits from Massage



Leslie Drawdy, PT, DPT, CLT-LANA, Tucson, Arizona, leslie@drawdyonline.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.

Clinical Approaches to Massage:

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.

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.

Guidelines for home massage

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 referred to 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, selfmassage 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 massaging 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.

Concerns/issues and modifications

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 massage over areas of intact skin can still be performed. Simple, light stroking of the skin without 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.

Choosing a physical therapist

It can be difficult to find the right physical therapist. If you cannot find a therapist who has knowledge and experience in treating PPS, look for a therapist who is familiar with neurological/neuromuscular disorders, preferably with experience treating multiple sclerosis patients.

Start by asking others you know with PPS who have had successful physical therapy.

If a therapist has a good understanding of multiple sclerosis, they already know the basic treatment principles for post-polio syndrome, whether they are aware of it or not! You're most likely to find a qualified therapist in a hospital-based outpatient therapy clinic.

If your function has declined to the point that leaving your home for an appointment completely wears you out and you are avoiding activities outside your home, you may qualify for home health therapy services. Most home health therapists are qualified to treat patients with PPS, since they see a wide variety of complicated diagnoses and situations. This would be an excellent place to start if you are finding that you need increased help with your activities of daily living and general mobility in your home.

PHI's online Post-Polio Directory (www.post polio.org/net/PDIR.pdf) includes the names of physical therapists. If you are a therapist and wish to be listed, or if you know a therapist who should be listed, please contact info@post-polio.org.

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Anesthesia Use in Polio Survivors: What's New?

Selma H. Calmes, MD, Chairman and Professor (retired), Anesthesiology Department, Olive View/UCLA Medical Center, Sylmar, California, <u>shcmd@ucla.edu</u>



Selma H. Calmes, MD, is a polio survivor and a member of PHI's board of directors.

Do we know anything new about anesthesia for polio survivors? By reviewing reports in medical journals we find that in the last two years, 2008-2010, there were five case reports (each about a single post-polio patient having anesthesia) in the medical literature and one study of a group. We will look at useful aspects of these cases and also comment on two other aspects of anesthesia care that are important.

Three of the five case reports were about regional anesthesia (RA). Regional anesthesia means that a local anesthesia drug, such as lidocaine, is injected to numb nerves in the back (spinal or epidural) or other body locations such as arms or legs (various nerve blocks). It is very safe and is preferred to general anesthesia, because it blocks the pain signals coming from the surgery site to the brain. This is very favorable for patients' well being. However, some operations can't be done with regional anesthesia. It is often technically hard to do RA in postpolio patients with scoliosis, especially if Harrington rods are present.

There is a new tool to help place RA: portable ultrasound (US) devices that help anesthesiologists find exactly where to administer the anesthesia drug. This technique is now commonly used in the United States, especially in teaching hospitals. One of the five cases was the first to report using US to place a spinal anesthetic in a postpolio patient with Harrington rods. Another case of regional anesthesia involved severe scoliosis and reported using a computed tomography (CT) scan to look at a post-polio patient's back anatomy before trying spinal anesthesia. Both techniques helped the anesthesiologists know where to place the needle for local anesthesia successfully and easily. The third case report on regional

anesthesia was about a nerve block of the leg for postoperative pain relief after surgery on that leg.

The group study was from Brazil and reported on 123 patients having 162 operations, mostly orthopedic surgery. Mean patient age was young – 35 years, and only three patients had serious medical diseases in addition to having had polio. Regional anesthesia was used for 64 percent of patients. No significant anesthesia complications occurred. These patients were followed for 22 months postoperatively, and there was no change in neurologic status.

This study documents that young post-polio patients do well during anesthesia, especially with RA. However, American patients are much older, in their 70s and 80s, and so also have diseases of aging, such as heart disease, diabetes and hypertension, all significant for anesthesia risk.

Often, these diseases of aging are much more important than any post-polio issues. So, we still need a large group study of the U.S. polio population during anesthesia.

What do we learn from these reports? First, this is increasing evidence that RA can be safely used in postpolio patients. And, so far, there is no evidence that PPS gets worse after RA. (This had been a concern after inflammatory proteins were found in the spinal fluid of some post-polio patients.) Technical difficulties can be overcome by using US or CT imaging. Also, regional anesthesia can safely be used for postop pain relief. So polio patients can experience the many benefits of modern anesthesia care!

The importance of two other aspects of anesthesia care for postpolio patients is becoming clearer: the need for preoperative pulmonary function tests and sleep apnea issues. Respiratory muscle function gets worse as we age, especially for those who had polio. It is important to know what a particular patient's pulmonary status is before most operations, especially upper abdominal or chest operations. This is measured with pulmonary function tests (PFTs) by a pulmonary physician. Those who used iron lungs should definitely have preop PFTs, because they seem to be at higher risk for postop respiratory failure. Lung function should be optimized by treating any infection, controlling bronchospasm and assisting coughing before high-risk patients have major surgery, and a pulmonologist needs to be involved in the postop care.

Sleep apnea is common in postpolio patients, and many need CPAP/BiPAP devices. Sleep apnea is welldocumented to be a risk factor for anesthesia incidents, both at the beginning of anesthesia and, especially, at the end of the case as patients begin to breathe on their own. Useful guidelines are in place to improve safety during anesthesia. Patients with sleep apnea, especially those on CPAP/BiPAP, should let the surgeons know this early in the surgery scheduling process, so they can alert everyone on the surgical team. Patients should bring their CPAP devices to the hospital and, after the breathing tube is removed, CPAP should begin. This requires someone to set up the machine, usually a respiratory therapist. If regional anesthesia is used, the CPAP device can even be used during the procedure, although not all anesthesiologists are comfortable with this.

Should we make any changes in the present recommendations for anesthesia for polio survivors? Regional anesthesia appears to be safe for post-polio patients, and the benefits – in terms of pain relief and anesthesia safety – are worth a possible small risk. So, the recommendations stand as is. It is essential to realize that the recommendations are not based on actual data; there is no significant data yet about how polio patients actually do during anesthesia. See the sidebar for other resources about anesthesia.



Anesthesiologists at their annual meeting learn how to use ultrasound to place a nerve block of the arm or shoulder. Photo by Steve Donisch courtesy of the American Society of Anesthesiologists

For more information on anesthesia:

Recommendations: www.postpolio. org/edu/hpros/sum-anes.html

Anesthesia update. Separating fact from fear: www.post-polio.org/ net/10thConfAnesthesiaCalmes.pdf

Sleep apnea issues: www.post-polio. org/edu/pphnews/pph22-1. html

Lambert DA et al. Postpolio syndrome and anesthesia. Anesthesiology 2005; 103:638-644

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Member Concerns

Wakil Carter, Sr., Janet DiClaudio, Terri Dunnermann, Marie McManus, Ruth Parham & Dot Parkhurst.

Please keep these members in your prayers.

Honoring Janet DiClaudio

Janet's birthday is June 17. We plan to celebrate with her and present her with a CEPSA appreciation plaque for her room at Eagle Health and Rehabilitation Center in Statesboro. We owe Janet such a debt of gratitude for all she has done to make our organization what it is today. Even more than that, we treasure her enduring friendship. I remember happy times with her when she and I went to lunch after meetings. We sat for two hours or more sharing our life stories. I learned what a bright, witty, and interesting woman she is. Join us June 17 in traveling to honor Janet. Please call Cheryl at 912-927-8332 if you are interested in carpooling or for directions to the center.

Archives Committee Appreciation

CEPSA owes great thanks to our archives committee volunteers- Lorraine Frew, Betty Goff, Lavonne Calandra, Diane Davis (history chair), and me. The

committee met May 22 at the LIFE office to continue work begun at our May 17 general meeting on updating our history books. We plan to meet several more times and hope to have all the books completely updated by the end of the summer. Please contact Diane if you are interested in joining the committee.

Moving Again

Sally and Ed Luck, active CEPSA members for several years while they lived in Sun City, SC, left our area to move to the Chattanooga, TN area. The Lucks are moving again. Cheryl has their new mailing address if you need it. Their email address is the same. We wish them well.

Retirement Congratulations

CEPSA offers sincere congratulations to Steve Hess of Statesboro on his recent retirement from the Bulloch County Board of Education. He has worked 15 years as a bus driver and buyer for the transportation department. This is Steve's second retirement. He previously worked for IT Grinell. We wish Steve many happy days of retirement.

Wedding Bells



Warmest congratulations and best wishes to Hattie Evensen and Robert Allen who will be married June 14 in Nahunta, Georgia. CEPSA members have watched this wonderful couple grow closer over the last few years. We wish them many years of health and happiness together.

CEPSA Salutes Fran Todd

Fran Todd, long-time Executive Director of Living Independence for Everyone, Inc. (LIFE), has resigned her position. Fran has provided 18 years of dedicated service to the agency. She served twice as interim director before being appointed as executive director. Your editor, a LIFE board member, has known Fran for many years and watched her increase her leadership skills and compassion for individuals with disabilities. She has been instrumental in shaping LIFE into the excellent agency that it is today. Fran will continue her association by working part-time as the Director of Development. We wish her well as she takes a muchdeserved break from her previous position there and continues to use her outstanding skills to further the cause of independent living.

Transport Chair Donated to CEPSA

We are the very fortunate recipients of a transport chair donated by Gloria West, a friend of Terri and Michael Dunnermann. The chair is very light-weight and can be used to transport members from the building entrance to the meeting room. The Dunnermanns will bring the chair to each meeting in their vehicle. Thank you, Ms. West.

Beaufort International Film Festival AKA DOC POMUS February 11-15, 2015

Hi folks -

If you go into this web site (see below) for the Beaufort International Film Festival, you will be able to view an amazing clip from one of the 2014 film finalists called "AKA DOC POMUS." Doc Pomus was a polio survivor who became a successful songwriter in the 60's. Do you remember "Teenager in Love", "This Magic Moment", and especially "Save the Last Dance for Me", which was ironic because of his disability. He was an amazing person who never let his disability hold him back. He even wrote some lyrics for Bob Dylan. This film will be showing at the Beaufort International Film Festival on Feb. 11-15, 2015, and possibly might be available on Netflix after that. I thought our group might be interested in knowing about it.

I liked the upbeat message.

Regards,

Marge (Lampke)

Portions of an email from Marge Lampke to Cheryl Brackin & Jim Veccia, 02 June, 2014.

Below are the links to the **Beaufort International Film Festival** website and the **AKA DOC POMUS** website. On the AKA DOC POMUS website, you can purchase a copy of the film for \$24.95 + \$4.99 shipping and handling. Both websites have the film trailer available for viewing.

http://www.beaufortfilmfestival.com/#!entries/c1wgv http://akadocpomus.com/#prettyPhoto

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Shining Light on Post-Polio Health

Next Meeting Saturday, June 28, 2014 10:30 AM at Nancy N. and J.C. Lewis Cancer & Research Pavilion Room 203 225 Candler Drive Savannah, GA

CONTRIBUTIONS

The Coastal Empire Polio Survivors Association is a non-profit corporation, which is tax exempt under IRS code 501c(3). We have no paid employees, only volunteers dedicated to helping all polio survivors. Your financial support is appreciated at any level suggested below:

- * CEPSA Member \$20.00 annual voluntary donation
- * CEPSA Supporter \$25.00 \$50.00 \$100.00 \$300.00 Other
- * CEPSA Memorial or Honor Gift any amount
- * CEPSA Sponsor any amount

Your contributions are tax deductible and will be acknowledged appropriately.

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-	Thank you for your suppo	Name	e of member