



The Lighthouse

Coastal Empire Polio Survivors Association, Inc.
Newsletter February, 2011

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Shining light on post-polio health
www.coastalempirepoliosurvivors.org



The President's Message...

We are still mired in the throes of winter. Many of us are trying to find ways to keep our bodies warm. Until I joined CEPSPA, I never realized my failure to resist the cold was polio-related. This past December was the coldest on record in this area. January has not been any kinder to us. With huge electric bills, many are turning to alternative ways to heat our homes. Just remember to be extremely careful with whatever alternative source you may choose.

The three coming months will bring us meetings you do not want to miss. This month our speaker will be Mr. Gordon Matthews, who has been involved in an immunization project in India. He will speak on his experiences there.

Our March speaker is a real coup for us. Through Diane's efforts we will be having one of the foremost authorities on Post-Polio Syndrome speak to us. Dr. Holly Wise, PT, PhD is an Associate Professor in the Division of Physical Therapy in the College of Health Professions at the Medical University of South Carolina. She currently evaluates and treats individuals with a prior diagnosis of polio through the Charleston Physical Therapy Clinic. Please read her biography on page 4 of this newsletter, along with an article she has written on 'post-polio related cramping.' We encourage all our members to attend. The meeting will be held at Candler, but in their Marsh Auditorium (see directions on flyer). We are hoping that many PT students from our various colleges can attend along with medical professionals wanting to learn more on how to properly treat their polio survivor patients. Your Care Team Leader will be in contact with you shortly and give you more details. Please ask them any questions you might have and be sure to mark your calendar (March 26th) for this special meeting. I can guarantee you will not be disappointed!!

In April we will be celebrating our 14th birthday. Many call it our anniversary, but to me an anniversary is simply to acknowledge a date or event, while a birthday shows growth. The nine years I have been a member of CEPSPA I have seen that growth. This year we became a 'teenager,' and I think we expanded as an organization and have kept that growth going. In order to continue that growth, we need everyone's participation. Please volunteer to help our chairpersons with their duties.

Jim Veccia, *President*

CEPSA Minutes for January 22, 2010

President Jim Veccia called the meeting to order at 10:37 am. After welcoming everyone, he introduced a new member, Marie McManus and her daughter, Jennifer. Marie contracted polio when she was 3 months old, was paralyzed from the waist down, and still have muscles that are paralyzed. She is a banker with BB&T. He also welcomed Beverly Jarvis, Terri Dunnermann, Larry Richter, Ross Smith, and Harvey Varnadoe back. Lorraine Frew introduced her friend Lucy Bear.

Lorraine Frew led them in saying the Pledge of Allegiance.

Charlotte Richter did the Inspiration. She read a selection from a book called 212 Degrees by Sam Carr and Mack Anderson that she found on the website SimpleTruths.com.

Terri Dunnermann passed around a sign-up sheet for the inspirations for the rest of the year and asked members to sign up.

Adrienne Stallworth did a presentation on personal record management. Everyone received a green folder with an advertisement for AnnualCreditReport.com, a list of documents to be kept for 1 month, 3 months, 1 year, 7 years and indefinitely. It also included a list of documents to be kept in a Safe Deposit Box and those that are to be shredded, creating a household inventory, a Net Worth Statement Worksheet, organizing a home filing system, an article on stolen identity and an I Love You Letter. Anyone who would like the handouts sent to them may contact Adrienne Stallworth at home, at work, or on her cell phone.

Business Meeting

Jim called the business meeting to order at 12:00 noon.

The minutes of the October 2010 meeting were approved as written.

The Treasurer's Report was presented by Marty Foxx and approved as submitted

Lavonne Calandra and Betty Goff will compare the Directory, the Care Team Lists and Mailing list to make sure everyone is on all lists.

The care team leaders expressed concern for Bobby Johnson, Ann Finley, Dick Warden, and Eunice Newcomer.

Dan Shehan had suggested that we join the Chamber of Commerce. After investigating it further, he said that it is not for us.

Sandra Bath attended the January 2011 Everybody Counts Immunization Coalition meeting. The flu season peaked in Georgia in December 2010. If you are 65 years old or older and never had a TDaP shot and you come in contact with babies 12 months old or younger, you can get a free TDaP shot at the Chatham County

Health Department. If you are over 60 years old you should get a shingles shot. The measles, mumps, and rubella vaccine does not cause autism. If you want to know what immunizations you need as an adult, you can go to www.immunize.org.

Diane Davis announced that Holly Wise, PT, PhD, is going to speak at our general meeting in March, 2011. Her presentation will be addressing Post-Polio Syndrome for family and friends. Diane asked for suggestions regarding advertising that meeting. One suggestion was to contact the colleges and hospitals to invite physical therapists and occupational therapists. We need to contact all members to get a preliminary count. The location of the meeting may need to be changed. It will be announced in the newsletter. Cheryl Brackin will call Candler regarding the availability of the Marsh Auditorium on March 26, 2011. Anyone interested in helping Diane, please e-mail her.

The speaker in February will be Gordon Mathews, District Governor-Elect of Rotary International District 6920, which is in southeast Georgia. He will be speaking about his experiences when he distributed vaccines in India.

The meeting was adjourned at 12:40 pm.

Respectfully submitted,
Janet DiClaudio, *Secretary*

The following attended our January Meeting:

Adrienne Stallworth, Ed Stallworth, Cheryl Brackin, Lorraine Frew, Tony Tedona, Richard Graham, Dan Shehan, Beverly Jarvis, Jim Veccia, Charlotte Richter, Larry Richter, Tom Schendorf, Penny Smith, Ross Smith, Marie McManus and daughter Jennifer. Betty Goff, Barry Turner, Terri Dunnermann, Michael Dunnermann, Sandra Bath, Marty Foxx, Harvey Varnadoe, Lavonne Calandra, Diane Davis, Ann Chance, Sissy Morel, Gigi Veccia.

HAPPY BIRTHDAY

February

Eddie Porter – 4

Sandra Bath – 16

Charles Johnson – 23

March

Barry Turner – 2

Thelma Tillotson – 4

Tony Tedona – 5

Lavonne Calandra – 7

Glenda Walker – 14

Terri Dunnermann – 18

Roy Tillotson – 24

Have a special Day! Celebrate!

Voluntary Dues of \$15.00 may be paid to Marty Foxx; her mailing address is: 21 East 61st Street, Savannah, GA 31405. Please try and make your payment this month either at our February meeting or else by mail. Thank you

Member Concerns

Sally Luck, Gloria Sullivan
Dick Warden, Harvey Varnadoe
Eunice Newcomer

Purpose of Support Group

Polio survivors have significant reasons for joining with one another. Our lives are changing in puzzling and frightening ways. Sometimes we have feelings of isolation, anxiety and depression. Our family and friends may not understand new symptoms.

Support groups encourage members to become educated and can help to find medical advice to make their own health decisions. Everyone can take part in many tasks. Some of these tasks can be done from a chair or bed.

From my own experience CEPSSA has given me a sense of belonging, to attend a meeting and feel the warmth and hugs from a group of giving members is so special.

I have grown... It is ok for me to sit and ride in a power chair or a scooter, it sure feels great not to get exhausted or be in pain. CEPSSA provided me the power chair.... THIS IS A SPECIAL GROUP! DON'T MISS OUT! Char Richter

Coastal Empire Polio Survivors Association, Inc.

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www.coastalempirepoliosurvivors.org

An alarming number of polio survivors are experiencing unexpected and often disabling new symptoms associated with the polio virus that was contracted forty or fifty years ago.

Announcing: Holly H. Wise, PT, PhD Presented by Coastal Empire Polio Survivors Association "Post-Polio Health Care"

Saturday, March 26, 2011 at 10:30 A.M.

Marsh Auditorium at CandlerHospital
5353 Reynolds Street, Savannah, Georgia

If you are a polio survivor, a family member, friend or medical provider
of a polio survivor, you don't want to miss this speaker.

Holly Wise, PT, PhD is an Associate Professor in the Division of Physical Therapy in the College of Health Professions at the Medical University of South Carolina. She currently evaluates and treats individuals with a prior diagnosis of polio through the Charleston Physical Therapy Clinic. Dr. Wise is a nationally recognized academic educator in health promotion and wellness for individuals with a disability and currently teaches Doctor of Physical Therapy students about the examination and management of the individual with a diagnosis Post-Polio Syndrome. She co-owned a private practice for 13 years, co-founded two post-polio evaluation clinics, and has promoted physical activity for individuals with mobility impairments for over 30 years. Dr. Wise has co-authored numerous articles and is a contributing author for the soon-to-be released [Post-Polio Health Care Considerations for Families & Friends](#), to be published by Post-Polio Health International.

What Is Cramping Your Style? Straight Answers to Your "Cramped" Questions

**Holly H. Wise, PT, PhD, and Kerri A. Kolehna, MS, MD,
Coastal Post-Polio Clinic, Charleston, South Carolina**

Tired in the morning? Is it difficult to get comfortable for a good night of sleep? A complaint often reported at the Coastal Post-Polio Clinic in Charleston, South Carolina, is the inability to get to sleep at night due to leg pain, twitching or cramping.

Muscle cramping is a relatively common, painful and bothersome complaint among generally healthy adults, and is more common in women than men. Some studies estimate as many as 50-70% of older adults may experience nocturnal leg and foot cramps (Abdulla, et. al., 1999). Although, leg cramps are a common complaint in older adults, they must be taken seriously when the individual is a polio survivor.

What is a muscle cramp? AKA "stitch," "spasm," "knot," "Charley-horse" or "twitch?"

Muscle cramping involves a physiological disturbance of muscle that produces an involuntary and painful contraction. Cramps typically occur in the calf muscle and are accompanied by sudden excruciating pain and persistent muscle contraction. Occasionally, both legs may be affected by cramping simultaneously. Although cramps often resolve spontaneously within minutes of onset, the episodes may continue for hours or days with no apparent pattern of frequency or duration.

Cramps can occur throughout the day but more often occur at night or when a person is resting. Although it is not known exactly why cramps happen mostly at these times, it is thought that the resting muscle is not being stretched and is therefore more easily excited.

The basis for the theory that cramps occur more at rest, due to the muscle not being stretched, is that passive stretching can relieve muscle cramping. Pain associated with cramping is likely caused by the demand of the overactive muscle exceeding its metabolic supply. This excessive demand results in ischemia, or diminished blood flow, to the muscles, and the accumulation of metabolites (waste products).

Causes of Leg Cramps

Twitching and cramping can be caused by over-activity of nerves and muscles from faulty posture, shortened muscle length and excessive activity or exercise.

Other known causes of muscle cramping include diabetes mellitus, kidney failure, thyroid or neurological disorders, and poor blood flow or peripheral vascular disease. In addition, certain medications and occupational routines can precipitate muscle cramping.

Recurrent cramps without a known cause are called idiopathic cramps. These cramps are suspected to be the result of disruptions or imbalances of unknown origins anywhere in the central and peripheral nervous systems and may explain the wide range of conditions in which the cramping occurs (Bentley, 1996).

Seeking Answers

A thorough history and possibly a referral for screening labs will help determine the causes for leg pain and cramping. Polio survivors can provide a

description of their muscle cramps, identification of the time and place when they occur, and an activity log of the 24-48 hours preceding the episode(s). For example, if after a vigorous exercise session or a particularly long walk, a polio survivor's muscles are noticeably twitching, aching or painful, then the activity probably exceeded the strength of the muscle.

In addition, the physical examination should include:

- Observation of edema, or swelling in the legs, and an examination of the circulation, or vascular supply, to the legs. Occasionally, a diagnostic ultrasound test (a Doppler) will also be performed to determine the adequacy of blood flow in the legs.
- Baseline measurements of joint and muscle range of motion to establish if there are shortened muscle lengths and limited motion contributing to the cramping.
- Manual muscle tests (MMT) of the arms, legs and trunk muscles to identify which muscles, if any, are at risk for overuse and subsequent cramping. In general, muscles with a strength grade less than a 3 on a 5-point scale are at risk for overuse.
- Posture, gait and/or a mobility assessment complements the information gathered from the MMT. Faulty posture is associated with cramping and particular attention should be given to inefficient patterns of movement due to muscle weakness.

Prevention and Treatment of Leg Cramps

The treatment approach for non-idiopathic cramps - cramps in which the underlying cause is known - is to treat the underlying cause. The only proven strategy for the prevention and treatment of exercise-induced muscle cramps is the avoidance or reduction of activities that cause cramping.

Strategies to reduce muscle overuse may include lifestyle changes, such as weight reduction, use of assistive and orthotic devices, and the adoption of energy conservation techniques. Other strategies include advice from a physical therapist to create efficient mobility patterns and to intentionally pace day-to-day physical activities. These approaches are designed to allow for sufficient rest of over-used muscles and to eliminate muscle twitching, cramping and pain.

As with the general population, nocturnal muscle cramping in polio survivors may also be idiopathic in nature and not just related to overuse of muscles affected by polio or the other known causes listed above. The first line of treatment is to stretch the leg muscles before sleep, avoid caffeine in the evening, and eat foods high in potassium (bananas, orange juice, etc.).

To accomplish self-stretching, polio survivors can put their foot flat on the floor and slowly put weight on the foot. This action stretches out the calf muscle, which can also be done in bed by "pointing your toes towards your nose" until the cramping stops. Applying heat and massaging the cramped muscles can provide relief, as can wearing night splints that help prevent muscle shortening. Individualized intervention sessions with a physical therapist and/or referral to a certified orthotist are usually required to correct muscle imbalance and faulty posture.

Although no treatment is conclusively effective, many people achieve temporary relief of symptoms with one or more of these treatments. Success would include the reduction in the intensity of cramping episodes, number of cramps per episode, and/or in the number of nights free of cramps.

What about quinine? Any new treatments?

The standard pharmacological treatment that has been used for over 50 years is 300 mg quinine taken at night. The outcomes are substandard with about 40% of individuals getting relief (Diener, et. al., 2002). The medicine must be taken for one month to truly tell if it is going to work, and does have side effects: ringing in the ear (tinnitus), dizziness, blurry vision and headaches.

Newer treatments include vitamin E or calcium gluconate, both of which are available over the counter. The beneficial effects of these non-prescription treatments on nocturnal cramping have not been studied in detail.

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A Statement about Exercise for Survivors of Polio

Advising all polio survivors not to exercise is as irresponsible as advising all polio survivors to exercise.
Spring 2009

From: PHI –

Current evidence suggests that exercises are often beneficial for many polio survivors provided that the exercise program is designed for the individual following a thorough assessment and is supervised initially by knowledgeable health professionals. Polio survivors and their health professionals who are knowledgeable about the complete health status of the individual survivor should make the ultimate decision on the advisability of exercise and the protocol of the exercise program.

Clinical research studies support exercise programs that are prescribed and supervised by a professional for many polio survivors, including those with the symptoms of post-polio syndrome.

Acute paralytic polio can result in permanent muscular weakness when the viral infection leads to death of anterior horn cells (AHCs) in the spinal cord. Recovery from paralysis is thought to be due to the re-sprouting of nerve endings to orphaned muscle fibers creating enlarged motor units. Recovery is also attributed to exercise that facilitates the enlargement of innervated muscle fibers. For example, some polio survivors regained the use of their arms and have walked for years with crutches. Others regained the ability to walk without the aid of braces, crutches, etc., and have continued to walk for decades.

The increased muscle weakness recognized in those with post-polio syndrome is believed to occur from the degeneration of the sprouts of the enlarged motor units. The premature death of some of the AHCs affected by the poliovirus is speculated to also cause new weakness, and some new weakness is caused by disuse, or a decline in activity or exercise.

There is agreement that repetitive overuse can cause damage to joints and muscles, but can repeated overuse and excessive physical activity accelerate nerve degeneration or nerve death? This is the crux of the physical activity/exercise debate.

Physical activity is movement occurring during daily activities. Exercise is defined as planned, structured and repetitive body movement. Therapeutic exercise is conducted for a health benefit, generally to reduce pain, to increase strength, to increase endurance and/or to increase the capacity for physical activity.

Polio survivors who over-exercise their muscles experience excessive fatigue that is best understood as depletion of the supply of muscle energy. But, some polio survivors' weakness can be explained by the lack of exercise and physical activity that clearly leads to muscle fiber wasting and cardiovascular deconditioning.

The research supports the fact that many survivors can enhance their optimal health, their range of motion and their capacity for activity by

embarking on a judicious exercise program that is distinct from the typical day-to-day physical activities. These same polio survivors need not fear "killing off" nerve cells, but do need to acknowledge that the deterioration and possible death of some nerve cells may be a part of normal post-polio aging.

Exercise programs should be designed and supervised by physicians, physical therapists and/or other health care professionals who are familiar with the unique pathophysiology of post-polio syndrome and the risks of excessive exercise. Professionals typically create a custom-tailored individualized exercise program that is supervised for two-four months. During this period, they will monitor an individual's pain, fatigue and weakness and make adjustments to the protocol, as needed, to determine an exercise program that a polio survivor can follow independent of a professional.

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 - \$15.00 annual voluntary donation
- * CEPSA Supporter - \$25.00 \$50.00 \$100.00 \$300.00
- * CEPSA Memorial or Honor Gift - any amount
- * CEPSA Sponsor – any amount

Your contributions are tax deductible and will be acknowledged appropriately.

Please complete this form and mail it along with your check to: **CEPSA, Marty Foxx, 23 East 61st Street, Savannah, GA 31405.**

Name _____

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Are you a relative or friend of a CEPSA member, if so _____
Name of member

Thank you for your support and encouragement.