



THE LIGHTHOUSE

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

February, 2015 Newsletter

www.coastalempirepoliosurvivors.org

Vol. XVIII, No. 2

The President's Message...

What inspires you? What lifts your spirits and takes you away from the mundane? What gives you courage? Some commune with nature. Some pray or meditate. Some listen to music. Some read books, devotionals, or poetry. I am sharing a collection of quotes which have inspired or comforted me.

"Far away there in the sunshine are my highest aspirations. I may not reach them, but I can look up and see their beauty, believe in them, and try to follow where they lead." Louisa May Alcott, author

"I see trees of green, red roses too... and I think to myself what a wonderful world." What a Wonderful World, Louis Armstrong, singer; lyrics, Bob Thiele and George Weiss

"Hold fast to dreams, for if dreams die, life is a broken-winged bird that cannot fly." Langston Hughes, poet

"Two roads diverged in a yellow wood...and I—I took the one less traveled by, and that has made all the difference." Robert Frost, poet

"'Hope' is the thing with feathers that perches in the soul and sings the song without the tune and never stops—at all." Emily Dickinson, poet

"You raise me up so I can stand on mountains; You raise me up so I can walk on stormy seas...You raise me up to more than I can be." You Raise Me Up, Josh Groban, singer; lyrics, Brendan Graham

With all our challenges we polio survivors still can be hopeful, inspired, and appreciative each day. That is the spirit I see in the members of our group.

Harvey Varnadoe brought up an interesting issue at the January general meeting. He continues to be concerned about inflammation in polio survivors and stated that we often have elevated white blood cell counts. This can affect critical organs and shorten our lives. Please share any thoughts about this by email or at the next meeting.

We look forward to seeing you at our February 28 meeting, when Bill Byler of Integrity Medical will be our speaker.

Cheryl Brackin

Our February Program

Mr. Bill Byler of Integrity Medical will be our guest speaker. He will discuss changes in Medicare coverage of durable medical equipment, products his company sells, and in-home services they provide to their consumers. Bill spoke to our group several years ago and gave an excellent presentation. Several of us have bought items from his business. We look forward to his return to CEPASA.

NEXT MEETING

Saturday,
February 28, 2015

10:30 AM

at Nancy N. and J.C. Lewis
Cancer and Research Pavilion

Room 203

225 Candler Dr., Savannah, GA

Coastal Empire Polio Survivors Association, Inc.

General Meeting Minutes January 24, 2015

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

President Cheryl Brackin called the meeting to order at 10:37am.

Founder, Lorraine Frew led the Pledge of Allegiance.

Terri Dunnermann gave the inspiration, an article from a Nebraska PPS newsletter by Milly Malone Mill entitled "Walking the Tight Rope." The article discussed how we deal with pain and sleep issues, reminding polio survivors to use caution when a C-pap is recommended.

Business Meeting:

Approval of Minutes: Minutes from the October 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: Care team leaders expressed concerns about Terri Dunnermann, Dot Parhurst, Marie McManus, Harriett Merritt, Tom Schendorf, Ross Smith, Barry Turner, Harvey Varnadoe, and Gigi and Jim Veccia.

New Business: Cheryl reminded all CEPSEA members to return borrowed devices when no longer being used, so that others can have them when the need arises.

We were reminded to save the date for our April 25 Anniversary Celebration to be held at the Marsh Auditorium. Three members will share their polio stories.

Diane and Cheryl will be working on updating/revising our materials in the new member packet, which is dispensed by Harvey to new members.

Cheryl announced that an orthopedist, specializing in foot disorders, and an orthotist, experienced in polio bracing, have been invited to speak at upcoming meetings. Lavonne, Betty, and Cheryl will look over a list of potential speakers to invite for future meetings.

The business meeting was adjourned at 11:18 am. The members then had an SOS session, which included completion of a brief member questionnaire about future directions of CEPSEA.

Respectfully submitted by
Michael Dunnermann, Secretary

Attendance: Cheryl Brackin, Lavonne Calandra, Carlos and Wanda Clas, Diane Davis, Michael & Terri Dunnermann, Marty Foxx, Lorraine Frew, Betty Goff, Richard Graham, Sissy Morel, Harvey Varnadoe.

Member Questionnaire Results

A small, but engaged, group of 13 attended our January 24 meeting. After the short business meeting the attendees completed a brief questionnaire to express their thoughts about future directions of CEPSEA. The results of the questionnaire are below.

Member Attendance: 7 of the 13 attend all nine meetings each year.

Meeting Schedule: 7 of the 13 want fewer meetings, and 6 want to maintain the current nine.

Suggested Meeting Schedule Change: 5 would like to have 6 meetings per year. 2 would like to have 5 meetings per year.

All agreed that we should continue our April anniversary meeting with three polio speakers and our Christmas banquet with a guest speaker. One member suggested having January as a "winter break." Another commented that if we have only 5 meetings per year, that leaves just 3 meetings for inviting speakers to address polio issues.

The majority indicated that they would be more likely to attend meetings with a speaker. One respondent stated that discussion meetings should be well-planned and conducted.

Suggested topics for speakers included pain management, pulmonary concerns, foot and back problems, kidney problems, bracing, balance, nutrition, and exercise.

Although there were no questions about the newsletter THE LIGHTHOUSE, there was a lengthy discussion about whether to maintain the current number of 9 newsletters per year or to reduce the number, along with reducing the number of meetings. Two members expressed that the newsletter is the lifeline to all our members, active and inactive.

**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.

Upcoming Meeting Dates

February 28, 2015 @ ***

March 28, 2015 @ ***

April 25, 2015 @ Marsh Auditorium

May 16, 2015 @ ***

June 27, 2015 @ ***

July & August- No Meetings

September 26, 2015 @ ***

October 24, 2015 @ ***

November- No Meeting

December 5, 2015 @ Hilton Garden Inn

*** (General Meetings)

@ Nancy N. and J.C. Lewis Cancer &
Research Pavilion, Room 203

Monday, June 2, 9:00 –10:15 am

Let's Talk About the Spine: Medical Overview

Carol Vandenakker-Albanese, MD

The spine: supports the trunk, stabilizes the limbs, protects the spinal cord and nerve roots, and allows multidirectional movement

Effect of Paralytic Polio on the Spine

The polio virus attacks the cell body of motor nerves in the spinal cord, resulting in paralysis or partial paralysis of muscles. This causes asymmetry of skeletal or spine support and spine bone growth may be affected.

These changes result in: loss of bone strength, altered body mechanics, secondary deformity, increased stress on spine segments, and increased stress on supporting soft tissue. Related spinal problems in the polio survivor include: spinal deformity, osteoporosis, accelerated degeneration, and symptoms related to nerve impingement secondary to spine degeneration can mimic post-polio syndrome.

Spinal deformity/Scoliosis

Risk of scoliosis in a polio survivor is 30%, Results from: asymmetric weakness of trunk muscles (intercostal, abdominal, paraspinal), pelvic weakness, tilt and/or leg length difference. The progression of curve correlated to degree of weakness and age at onset of curve. Bracing is often not successful in

preventing progression and surgical fusion often recommended.

Risk of dramatic increase during adolescent growth spurt, however progression can continue after skeletal maturity due to degenerative changes: asymmetrical disk degeneration, vertebral compression fractures, lateral slippage of vertebrae (spondylolisthesis). Progression can cause: pain, nerve impingement, an unbalanced spine, bony pressure points, reduced lung function.

Osteoporosis

Polio survivors are at increased risk of osteoporosis based on: reduced peak mass, reduced muscle action on bone, and reduced mobility.

Spine (vertebral) fractures may occur with falls/trauma or spontaneously if bone is very weak. Vertebral compression fractures may contribute to progression of spinal curves.

Spine Degeneration

Spine degeneration is common in the general population. Polio survivors often have increased stress on the spine related to loss or asymmetry of muscle support and altered mechanics of movement. Spinal curves often progress with degenerative changes. Degeneration in the spine can start with disc degeneration or arthritis in the facet joints. Degeneration in one area puts increased stress on the other structures and eventually degeneration occurs in both. Slippage of vertebrae, enlargement of joints and ligaments, and bulging discs all reduce the space around nerves (stenosis) and can result in nerve compression. Single level nerve compression can cause pain, weakness and/or loss of sensation in specific pattern in a limb. Pain may be constant or intermittent. Pain may be related to position or activity.

Spinal stenosis refers to narrowing of the spinal canal. It is commonly a result of degenerative changes including disc bulging, facet and ligament hypertrophy and osteophytes. Onset of symptoms is often gradual with progressive increase but may be acute. Symptoms can include: loss of balance, pain in buttocks or legs, deep ache in the legs that increases over time while standing or walking. Pain is usually relieved with sitting, less when walking with shopping cart or walker (forward flexed position), and may confused with symptoms of post-polio syndrome.

Symptoms related to spine degeneration include: back pain, leg pain and/or weakness, loss of sensation, change in bowel/bladder control, difficulty breathing, increased fatigue, increased loss of balance, increased

frequency of falls. Problems related to the spine may be confused with the symptoms of post-polio syndrome: new weakness, increased fatigue, leg pain with walking/relieved with rest, increased difficulty breathing.

Treatment of Spinal Disorders

Medical evaluation is important to identify cause of symptoms and focus treatment (Spine specialist). Treatment options for spine conditions include: physical therapy, medications for pain control, bracing, injection procedures, and surgical intervention for nerve impingements and unstable spine.

The pain medications commonly used include: acetaminophen (used in moderation — least side effects), anti-inflammatories (may cause gastritis/ulcers), narcotics (cause drowsiness, fatigue, constipation, and tolerance) and neuroleptics (also cause drowsiness, “spacey” feeling).

Spine bracing is safe but not always tolerated. Braces may be semi-rigid or rigid. They reduce motion and provide support. They can be custom molded, semi-custom, or off-the-shelf. They may be uncomfortable, especially with sitting, but they do not cause harm.

Spinal injection procedures may be very helpful for inflamed nerves or joints. Nerve blocks can help alleviate pain from joint degeneration, but relief is usually temporary. If pain is severe surgical intervention may be considered. Surgery is also indicated when there is nerve compression with loss of function or an unstable spine. Spine surgery is often major surgery with significant risk involved.

Preferred management of spine conditions is conservative. A conservative program may include topical medications and modalities, change in lifestyle, activity modification and an exercise program that includes strengthening, stretching and cardiovascular conditioning. This treatment is usually taught through physical therapy.

Summary

Spine problems in polio survivors are common. Common problems include:

- Scoliosis or other spinal deformity
- Osteoporosis
- Degenerative changes
- Nerve compression

Problems related to the spine may be confused with symptoms of post-polio syndrome:

- New weakness
- Increased fatigue

- Leg pain with walking/relieved with rest
- Increased difficulty breathing

Treatment options include:

- Pain medications
- Bracing
- Injections
- Surgery
- Physical therapy

Prepared for Post-Polio Health International's 11th Conference: Promoting Healthy Ideas, May 31- June 3, 2014.

Monday, June 2, 9:00 —10:15 am

Let's Talk About the Spine: Physical Therapy Intervention

Cynthia Henley, PT and Kathryn Wollam, PT

Introduction

Physical therapy treatment for spinal pain and dysfunction requires a multifaceted approach. Treatment follows a detailed evaluation and is specific to the needs of each patient. No two backs are the same even with the same diagnosis.

Modalities

Modalities are often utilized in the physical therapy treatment of spinal pain. Following an evaluation, a physical therapist will determine the appropriate modality for each patient situation.

The therapeutic application of heat and cold has long been utilized for pain control. Heat accelerates the metabolic process by increasing circulation. This helps flush out the waste products of a muscle spasm and reduces pain. Local cooling decreases the metabolic process thereby decreasing the inflammatory response. It offers an analgesic effect by decreasing nerve conduction and muscle contractibility. People with a history of polio are often less tolerant to the application of cold. Using moist heat adjacent to the cold usually makes it tolerable.

Myofascial release and soft tissue mobilization have been found to be effective in the treatment of back pain. Massage brings increased circulation to the area; aids in the release of muscle spasms; allows stretching of abnormal fibrous tissue; and increases extensibility of the soft tissues.

Ultrasound is a modality that uses sound waves to treat pain and promote healing. The thermal effects of continuous ultrasound cause increased friction and heat on a molecular level. This promotes healing by

increasing the metabolism of the cells in the soft tissue.

Electrical stimulation can reduce pain by sending small electrical impulses through electrodes placed on the skin to underlying nerve fibers. Pain reduction can occur by blocking the pain signals to the brain or by causing a release of endorphins, natural chemicals in the brain which act as an analgesic.

This form of electrical stimulation is commonly known as TENS (transcutaneous electrical nerve stimulation). TENS should not be confused with EMS (electrical muscle stimulation) which can be used to stimulate a muscle contraction.

Therapeutic Exercise

Therapeutic exercise refers to physical activities prescribed to improve function, correct an impairment or obtain a state of well-being by restoring strength, endurance, flexibility, stability and balance.

The first objective of the therapeutic exercise is to assist the body in reducing pain and inflammation. Once that is achieved, often in conjunction with modalities, the exercise focuses on improving range of motion, increasing muscle strength and endurance.

With polio affected muscles, if an exercise is too strenuous, certain signs of overuse may occur within 24-48 hours. These signs include muscle cramps or spasms, muscle twitching, moderate to severe muscle pain and extreme fatigue. This needs to be reported to your physical therapist so the exercise program can be modified.

Stretching, Strengthening, Conditioning: Muscle flexibility and joint range of motion are achieved through stretching and movement. The stretching helps lubricate the joints and prepare the nervous system.

Hold a stretch position for 20-30 seconds. Don't bounce into the stretch. People with spinal issues often have tightness in their lower back and hamstrings muscles. However, if paresis of the hamstring occurred with polio, these muscles are often overly flexible. Do not overstretch weak flexible muscles.

Strengthening exercises are performed with resistance using weights, stretch bands, or your own body. Often the core muscles are weak with spinal issues. However, when complicated by a history of polio, the exercise guidelines must be observed. Increase resistance and number of repetitions cautiously. Watch for signs of overuse.

Endurance exercises engage large muscle groups over a longer period of time. When the muscles have good

endurance, they will support the spine and provide postural stability throughout the day. When easily fatigued, the spine is subject to more biomechanical stress.

Aquatic Exercise: An excellent way to achieve improved flexibility, strength and general condition is with aquatic exercise. Aquatic exercise is very beneficial, as the buoyancy of the water will help to support weak muscles and decrease joint stress while it can also provide resistance to strong muscles. Exercises can be modified in the water and core muscles can be strengthened by using the resistance of moving both arms at one time.

Body Mechanics

Body mechanics refers to the way we move during daily activities. Good body mechanics may protect the back from pain and injury. Adjustments during daily activities may be required to accommodate body changes related to aging, spinal dysfunction and polio related issues. Movement methods used in the past may not be safe and effective with the physical changes.

Good body mechanics and proper positioning can help protect your spine and may help alleviate some associated problems with digestion, swallowing and breathing. Following are some basic guidelines to help you with good body mechanics: of course, this can be difficult depending on your physical limitations. Supports, braces and positioning devices can help with proper body mechanics.

When lifting an object: Stand with feet apart, back straight. Bend from knees, not the waist. Get close to the object. Lift the object using your arm and leg muscles. Do not use your back muscles. Pivot to turn, do not twist. Ask for help if you are unable to lift the object.

When carrying an object: Hold the object close to your body. Do not carry things that are too heavy for you. The seat of a rolling walker can carry your lunch tray, a laundry basket or groceries and take the stress off of your spine.

Sitting: Sit on a supportive chair with armrests. Use a small pillow, rolled towel or lumbar roll to support your lower back. Sit on a wedge shaped cushion if there is significant atrophy of one buttock in comparison to the other. Do not sit for long periods of time. Get up and change positions.

Conclusion

Physical therapy evaluation and treatment of spinal

dysfunction provides intervention and guidelines for the long term management of symptoms. To maintain the results achieved in physical therapy, compliance with a realistic exercise program, simple lifestyle modifications and small adjustments to movement is essential. Improvements in spinal health and a general sense of well-being can be attained.

Prepared for Post-Polio Health International's 11th Conference: Promoting Healthy Ideas, May 31- June 3, 2014.

Tuesday, June 3, 10:45 am —12:00 pm

Post-Polio Research:

Update on PHI-funded Research

Antonio Toniolo,

University of Insubria, Varese, Italy

Remnants of poliovirus genome in patients with post-polio syndrome but not in their family members

Antonio Toniolo and Andreina Baj

Laboratory of Medical Microbiology, University of Insubria and Ospedale di Circolo, Varese (Italy)

In humans, the only evidence for persisting poliovirus infection has been found in individuals with deficiencies in B lymphocytes and low or absent immunoglobulins.

Over the last 4 years, we conducted an observational study of PPS in a cohort of polio survivors who were attending Northern Italy Hospitals for neuromuscular problems. Consenting family members and controls were also investigated. Results of virology studies (detection of poliovirus genome and virus activity) show that a persistent low-level infection is associated with PPS. So far, however, we have been unable to demonstrate that the persisting virus does play a role in the development of this progressive disorder.

In the investigated cohort, 97/107 individuals have been shown to have developed PPS 15 or more years after the acute attack. Family members of PPS patients (n=45) were also studied, together with a control group represented by healthy blood donors and controls with neurologic disorder other than PPS (n=47). Specimens included: cerebrospinal fluid, peripheral blood leukocytes, live cells of duodenal mucosa, skeletal muscle, peripheral nerve.

Poliovirus genomes were detected in 82/97 patients with PPS (85%) and in 3/92 controls (3.3%). Type 1 poliovirus was the most prevalent (61% of cases),

followed by type 2 and type 3 (12% and 9%, respectively). Some cases (18%) could not be typed. Based on clinical history, 22/107 poliomyelitis cases were associated with polio vaccination (18%). In vitro, leukocytes of poliovirus-positive PPS patients did produce enhanced levels of inflammatory mediators as compared to leukocytes of healthy donors. This is in line with a pathogenic hypothesis indicating that chronic inflammation is a hallmark of PPS.

Serum immunoglobulin levels were measured in PPS patients, their family member, and controls. As compared to healthy blood donors, levels of IgG1, IgG2, IgG4 and IgA were significantly reduced both in PPS patients and their family members. IgM levels were not significantly different. This suggests that modest immunoglobulin deficiencies may be present in individuals who developed clinical manifestations after being hit by poliovirus as well as in their family members. We also measured titers of neutralizing antibodies to the 3 poliovirus types in sera of PPS patients, their family members, and healthy controls. No significant differences were found.

The results lend support to the idea that residual poliovirus activity does persist in PPS patients and that virus persistence could be of pathogenic significance. To clarify a possible causative link between virus persistence and PPS, we are going to check whether poliovirus is detectable in a cohort of polio survivors who, in spite of age, failed to develop the late consequences of polio. The expected result is that people with stable polio will not be harboring poliovirus.

Our data also show that poliovirus cannot be found in family members of PPS patients, i.e. that virus is not transmissible within families. This finding tells that PPS people are “not infectious” and has reassuring implications. Taken together, these data indicate that novel virology methods might offer the possibility of identifying, among polio survivors, those with chronic poliovirus infection. In perspective, it may be envisaged to treat them with antiviral therapies either for preventing PPS or for blocking its progression.

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dedicated their time and efforts to this noble task:
Martina Colombo, Giuseppe Maccari, Merja Roivainen.

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Best Wishes to all our members
celebrating their birthdays in
February or March.
We hope you have a wonderful day!

Member Concerns

Terri Dunnermann, Dot Parkhurst,
Tom Schendorf, Penny and Ross Smith, Barry Turner,
Velma Underwood, Gigi and Jim Veccia
& Harvey Varnadoe.
Please keep these members in your prayers.

Happy Happenings in Our CEPASA Family

Richard and Jamie Warden had a wonderful trip to Nicaragua in December. Watch for a newsy article in the March newsletter about their travels.

Lorraine Frew's grandson, Christopher Rearick, recently became a major league pitcher with the San Diego Padres.

Nancy and Steve Hess will be welcoming their 4th grandchild in August. Their son and daughter-in-law are expecting their first child.

Marty Foxx's grandson, John Foxx Wilhite, won recognition in the local Social Studies Health Fair Project on Savannah's Homeless. He now will compete at the district level. John Foxx is an 8th grade student who plays the violin and also plays basketball at Charles Ellis Montessori School. His Mimi Marty is very proud of him.

Wanda and Carlos Clas soon will be welcoming her parents, Arcelia and Angel Santiago, who are moving from Puerto Rico to Savannah in February.

Cheryl Brackin's nephew, Max Oliver, an honors freshman at Wayne County High School in Jesup, was selected for the Duke University Summer Academy to be held in July.



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Shining Light on Post-Polio Health

Next Meeting
Saturday,
February 28, 2015
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
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Name of member

Thank you for your support and encouragement.