



THE LIGHTHOUSE

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

September, 2013 Newsletter

www.coastalempirepoliosurvivors.org

Vol. XVI, No. 7



The President's Message...

Happy Autumn, Everyone! We usually describe the upcoming season as Fall, but we polio survivors do not like the word "fall." It is good to see our hot, wet summer end. We can hope for a cooler, drier autumn with no unwanted tropical weather.

Post-Polio Health International in St. Louis has invited polio survivors to join the 2013 "We're Still Here" campaign during the week of October 6-12. PHI suggested that we speak to students at local schools about our disability experiences and the lessons we learned that helped us lead successful lives. Your CEP SA Executive Board met earlier in the month, discussing the "We're Still Here" campaign and making plans for the last quarter of our year. We also began thinking about 2014 and some possible changes. You will be hearing more soon.

Several of us experienced personal losses over the break. Once again our CEP SA family came through to support each other. If we missed your news about the loss of a family member or close friend, please tell your care team leader. A support group supports, and we want to be here for you.

It will be great to see many of you at our September 28 meeting at The Exchange on Waters. The members are the program!! We will be **Sharing Our Strengths/Showing Our Solutions/Supporting OurSelves**. This **SOS** program is about things we do to make life less difficult as a polio survivor. We want each member to have at least one idea to share. Bring items to "show and tell" or simply describe them. I just saw a device that holds a Ziploc bag open to allow one to pour something into it. What a great gizmo! When I freeze blueberries in Ziplocs, I usually spill a few on the counter. No more. Let us know the cost of items you show or describe. You do not have to talk about a device. Tell about anything you do "to take care of you," such as resting on Monday following a busy weekend.

Many of you have heard about the polio outbreaks in three African countries. Such news is particularly heart-breaking to polio survivors. We are saddened to think of the journey ahead for the infected children. Poverty, ignorance, distrust, and the desire for domination, resulting in extreme violence, continue to prevent global eradication. We want to see a world free of polio in our lifetimes.

Cheryl Brackin, President

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Next Meeting 

Saturday,

September 28, 2013

10:30 AM

Autumn begins on September 22, 2013.

Coastal Empire Polio Survivors Association, Inc.

General Meeting Minutes June 22, 2013

Location: Exchange Restaurant

Call to Order/Welcome: President Cheryl Brackin called the meeting to order at 10:43am and then welcomed everyone. She recognized the Richters and wished them well at their last meeting, prior to moving out of the state. She welcomed back Marge and Jim Lampe and Dot and Bob Parkhurst.

Pledge of Allegiance: Carlos Clas led the Pledge of Allegiance.

Inspiration: A song "My Best Friend" was written and sung by Esther Simmons. The song was inspired by her mother, Della Simmons.

Program: Diane Davis introduced our guest speaker Leigh White, Physical Therapist, Candler Outpatient Rehabilitation. Leigh did a power point presentation that covered the topics of what a physical therapist can and cannot do. Topics included types of pain; orthopedic, back/spine, neurological and balance defects; benefits of exercise; drinking water to achieve good health and prevent dehydration. Sleep and stress management also were reviewed. She closed by sharing that the S.A.D., Standard American Diet, is bad. We are not eating the recommended 9-13 servings per day of fruits and vegetables that help our bodies detoxify. Everyone had the opportunity to ask very helpful questions as we learned many new health tips.

Business Meeting:

Approval of Minutes: Minutes from the March meeting posted in our newsletter were approved as written. We also voted on and approved the meeting minutes from our May meeting.

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

Care Team Reports: The care team leaders reported concerns about Ruth's son Wakil Carter, Richard Graham's brother Wes, Sandra Bath, Lorraine Frew, Marge Lampke, Eunice Newcomer, Skeet Varnadoe, Harriett Merritt, and Bill Tillman, Cheryl's brother-in-law.

Old Business: Adrienne Stallworth shared with the group copies of the updated SCCDI Accessibility Guide maps, produced by the Savannah-Chatham Council on Disability Issues and Living Independence for Everyone, Inc., and sent to us by Dan Shehan.

Cheryl Brackin reported that we still have the CEP SA brochures and holders available for sharing our group information to reach out to other polio survivors.

Michael Dunnermann reminded our membership that we will have our summer break and will not formally meet again until September 28. We will again have our summer

luncheon at Johnny Harris Restaurant on Victory Drive on Saturday, August 3rd at noon. This is Dutch treat and has always been a good time to catch up on our summer activities. Care Team Leaders will make calls in mid-July as a reminder and to get a count.

New Business/Announcements: Cheryl pointed out that we had several new articles and an S.O.S. posting on the registration table for anyone to take home and share with others.

The meeting was adjourned at 12:51 pm.

Respectfully submitted,
Michael Dunnermann, Vice-President/Secretary

Attendance: Cheryl Brackin, Wanda & Carlos Clas, Esther Simmons, Della Simmons, Michael & Terri Dunnermann, Delores McIntyre, Marty Foxx, Lavonne Calandra, Betty Goff, Barry Turner, Harvey Varnadoe, Adrienne Stallworth, Richard Graham, Brenda Mills, Bob & Dot Parkhurst, Larry & Charlotte Richter, Marge & Jim Lampke, Hattie Evensen, Joan & Alan Page, Diane Davis, Jim & Gigi Veccia.

Upcoming Meeting Dates

GENERAL MEETING

September 28, 2013 @ Exchange Restaurant

October 26, 2013 @ Exchange Restaurant

NO Meeting in November

Our September Program

Show & Tell

Sharing Our Strengths or S.O.S



Our September program will be an exciting one! We will focus on what makes life easier for each of us. It will be a "Show and Tell" style program.

We invite you to bring an item that makes your life easier. Tell us about it. Tell us where we can get it and how much it costs. Describe the item if you can't bring it in or bring a photo to pass around.

Don't have an item? Tell us about something you do that makes your life better or easier. Everything helps!

Everyone has something to offer. Your "find" or suggestion can change someone else's life. This is an opportunity for CEP SA members to make a difference.

Please have your items, ideas and suggestions ready for an informative session.



Polio in Somalia, Kenya, and Ethiopia

Information updated 8-22,13

What is the current situation?

According to the [Global Polio Eradication Initiative](#), as of August 20, 2013, 108 cases of polio have been reported from Somalia since April 2013. These are the first wild poliovirus cases reported in Somalia since 2007.

Also, 12 polio cases have been reported from Kenya. These are the first wild poliovirus cases confirmed in Kenya since July 2011. One case from July has been reported from the Somali Region of Ethiopia. This is the first wild poliovirus case reported in Ethiopia since 2008.

CDC recommends that all travelers to Somalia, Kenya, and Ethiopia be fully vaccinated against polio. In addition, adults should receive a one-time booster dose of polio vaccine.

Because of the risk of cross-border transmission, CDC recommends a one-time booster dose of polio vaccine for adults who are traveling to Djibouti, Eritrea, South Sudan, and Yemen and who are working in health care facilities, refugee camps, or other humanitarian aid settings. This kind of work might put people in contact with someone who has polio.

What is polio?

Polio is a disease caused by a virus that is mainly spread by person-to-person contact and eating or drinking items contaminated with the feces of an infected person. Polio can also be spread through water, other drinks, and raw or undercooked food.

Most people with polio do not feel sick. Some people have only minor symptoms, such as fever, tiredness, nausea, headache, nasal congestion, sore throat, cough, stiffness in the neck and back, and pain in the arms and legs. Most people recover completely. In rare cases, polio causes permanent loss of muscle function in the arms or legs (usually the legs) or death.

What can travelers do to prevent polio?

Get the polio vaccine:

- Ask your doctor or nurse to find out if you are up-to-date with your polio vaccination and whether you need a booster dose before traveling. Even if you were vaccinated as a child or have been sick with polio before, you may need a booster dose to make sure that you are protected. See individual [destination pages](#) for vaccine recommendation information.
- Make sure children are vaccinated.
- See [Vaccine Information Statements \(VIS\)](#) for more information.

Eat Safe Foods:

- Food that is cooked and served hot

- Hard-cooked eggs
- Fruits and vegetables you have washed in clean water or peeled yourself
- Pasteurized dairy products

Don't Eat:

- Food served at room temperature
- Food from street vendors
- Raw or soft-cooked (runny) eggs
- Raw or undercooked (rare) meat or fish
- Unwashed or unpeeled raw fruits and vegetables
- Peelings from fruit or vegetables
- Condiments (such as salsa) made with fresh ingredients
- Salads
- Unpasteurized dairy products
- "Bushmeat" (monkeys, bats, or other wild game)

Drink Safe Beverages:

- Bottled water that is sealed (carbonated is safer)
- Water that has been [disinfected](#) (boiled, filtered, treated)
- Ice made with bottled or disinfected water
- Carbonated drinks
- Hot coffee or tea
- Pasteurized milk

Don't Drink:

- Tap or well water
- Ice made with tap or well water
- Drinks made with tap or well water (such as reconstituted juice)
- Flavored ice and popsicles
- Unpasteurized milk

[For more information, see Food and Water Safety.](#)

Practice hygiene and cleanliness:

- Wash your hands often.
- If soap and water aren't available, clean hands with hand sanitizer (containing at least 60% alcohol).
- Don't touch your eyes, nose, or mouth. If you need to touch your face, make sure your hands are clean.
- Cover your mouth and nose with a tissue or your sleeve (not your hands) when coughing or sneezing.
- Try to avoid close contact, such as kissing, hugging, or sharing eating utensils or cups with people who are sick.

To read this article in its entirety and for more information, please visit the Centers for Disease Control and Prevention website at: <http://wwwnc.cdc.gov/travel/notices/alert/polio-somalia-kenya>



PHI invites you to participate in its **2013 WERE STILL HERE!** Campaign during the week of **October 6-12** by speaking to students in your local elementary, middle and high schools. For ideas on how you can participate and more information go to:

<http://www.post-polio.org/edu/pphnews/PPH29-3sum13p6-7.pdf>

June 22, 2013 Program Highlights



Benefits of Physical Therapy Combined with Nutrition

with Leigh White, Physical Therapist
Candler Outpatient Rehabilitation

Leigh White spoke to our CEPSSA group and shared information about physical therapy using passive and active methods for pain management. She also discussed a Holistic approach which focused on exercise, water facts, nutrition, digestion and stress management. She was happy to answer our questions and willing to educate and empower us on these subjects.



Leigh White (Standing) presenting to our group as CEPSSA members Diane Davis, Dot Parkhurst and Bob Parkhurst (L to R) look on.

We can't review the entire program, but the following are a few very interesting topics that were discussed.

What Physical Therapists do:

- Relieve Pain
- Improve ROM (Range of Motion)
- Strengthen muscles
- Improve Function

Physical Therapy Goals:

- Help patients achieve THEIR goals
- Restoration
- Prevention

Physical Therapists can address Orthopedic problems such as joint pain (tendonitis, bursitis, rotator cuff, meniscus, etc), structural changes and ROM limitations.

They can also help patients with Functional Impairments including walking, stair/curb negotiation and transfers that involve lying down, sitting or standing.

People with back/spine, neck, headaches, radicular or referred symptoms, functional impairments, ROM limits, balance deficits and/or walking difficulty can also benefit from physical therapy.

How is Physical Therapy used to relieve pain?

A Physical Therapist may focus on decreasing pain with either passive or active therapy.

Passive Physical Therapy include:

- Heat/ice packs
- TENS units
- Ultrasound

Active Physical Therapies include:

- Stretching

- Strengthening exercises
- Pain relief exercises
- Low-impact aerobic conditioning

Prepare before your visit to a therapist:

- Bring a family member or trusted friend
- Come early for paperwork
- Bring a list of your medications
- Wear appropriate clothes
- Make sure your insurance will pay

What to expect during your first therapy visit:

- Many questions about your symptoms
- Detailed examination
- Evaluation of your gait, functional activities and body mechanics
- Evaluation of your home or work environment
- Determine your goals
- Set up a plan
- Lots of education!
- Special equipment
- Start treatment
- Home exercise program

Holistic Approach

Leigh also discussed a Holistic approach and said that wellness is not merely the absence of disease but a preventive approach to optimize function. Wellness is a holistic, integrated approach that requires choice and active personal responsibility. A Holistic approach focuses on exercise, water intake, sleep, nutrition and decreasing stress.

Benefits of Exercise:

- Lotion for your Joints
- Use it or lose it
- Bone density
- Balance

Water Facts: by Dr. Batmanghelidj*

- Our bodies are 75% water
- Main source of energy
- Bonding adhesive for cell structure/protects DNA
- Improves the immune system
- Transports/assists absorption of vitamins/minerals
- Efficiency of RBC's - transporting O₂
- Clears toxic waste from the body
- Main lubricant in joints
- Prevents clogging of arteries
- Needed for manufacture of neurotransmitters
- Helps prevent the loss of memory
- Reduces stress, anxiety, and depression, restore normal sleep rhythms
- Makes skin smoother, reducing aging
- Reduce allergies and asthma
- Helps against hypertension

*Dr. Batmanghelidj is a "researcher, author and advocate of the natural healing power of water." www.watercure.com

Signs of Dehydration:

- Muscle cramps
- Headaches
- Fatigue
- Anxiety/decreased concentration
- Constipation
- Dry skin

Tips for Hydration:

- Drink water first thing when you wake up
- Drink small bits all day long
- 4-6 oz every 20-30 min
- Less during eating to not dilute stomach acids
- Limit soda, caffeine, and alcohol

We were reminded to get enough sleep, decrease and manage stress and watch our cortisol levels, as well as watch our diets.

S.A.D. or Standard American Diet contains:

- Too much animal protein and fat
- Too much processed and refined food
- Not enough fruits, vegetables, whole grains & legumes
- Calorie displacement - "bad" foods replace protective foods like fruits and vegetables in the diet

Fruits and vegetables contain antioxidants. Antioxidants are barriers that protect us from free radicals. Having 9 servings of fruits and vegetables per day is key. Leigh said that half of your plate of food should consist of fruits and vegetables. The other half should be of grains, proteins and dairy on the side.

Leigh suggested taking a supplement if you aren't consuming enough fruits and vegetables. She said if you need to take a supplement, to make sure it is "whole food" based. Her choice of fruit and vegetable supplement is Juice Plus. Leigh is also a Wellness Consultant for Juice Plus. For more information about Juice Plus, you can write to Leigh at leigh.white82@gmail.com. She also has recipes available at leighjuiceplus.wordpress.com.

Program Notes:

- Medicare will NOT pay for Physical Therapy due to chronic problems (more than 3 months)
- Medicare will pay for Physical Therapy due to Acute problems (less than 3 months)
- After 2 days of rest from exercise, your body starts to lose enzymes and ability
- Drink half of your body weight in ounces of water per day
- Drinking too much liquid with your meals can impede the digestion process
- Stop drinking water 20 minutes before a meal and begin again 1 hour after the meal
- Every hour of sleep that you get before midnight is equivalent to 2 hours after midnight
- Going to bed about 9:30pm and waking when the sun comes up is ideal
- There are 10,000 nutrients in a single apple and only about 10 in a multivitamin

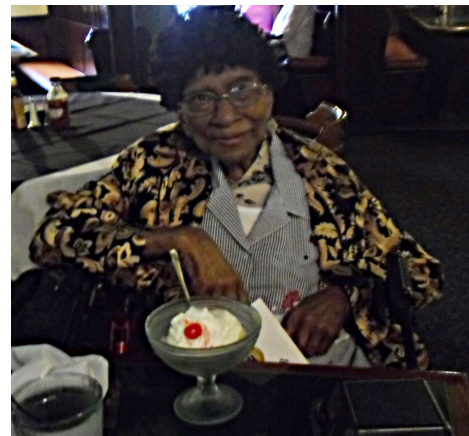
Program Notes were taken at the June 22 General Meeting.

Thank you to Leigh White for a very informative and educational program and to Diane Davis for inviting Leigh to be our June speaker.

CEPSA Summer Luncheon

**August 3, 2013
Johnny Harris Restaurant**

Several CEPSA members met for lunch on August 3, 2013 for our one and only summer luncheon this year. They were able to catch up with each other and celebrate CEPSA's own Archie Ivey's 89th birthday. Archie Carter Ivey is the senior member of the Coastal Empire Polio Survivors Association. She was born on August 11, 1924 and is a wonderful inspiration to our members. A great time was had by all!



Happy
Birthday,
Archie!
89



Photos are courtesy of Michael & Terri Dunnermann.

Sample Exercises

NON-FATIGUING GENERAL CONDITIONING EXERCISE PROGRAM (THE 20% RULE)

Stanley K. Yarnell, MD (retired), California

The non-fatiguing general conditioning exercise program using the 20% rule was designed to restore stamina or endurance for those individuals who have continued to be bothered by profound fatigue following surgery, illness or trauma.

The program begins by determining the polio survivor's maximum exercise capability with the help of the clinic physical therapist. The type of exercise can be in a pool or on



dry land, using an arm ergometer or an exercise bicycle, depending on the individual's abilities and preferences. If one prefers swimming, the maximum number of laps that the patient can swim is used as the

maximum exercise capability. If the survivor has considerable residual weakness and is only able to swim one lap in half an hour, then the amount of time actively swimming can be used as the maximum exercise capability rather than the number of laps.

Having established the maximum exercise capability, the polio survivor is instructed to begin his aerobic swimming program at 20% of the determined maximum exercise capability. He can swim three to four times per week at that level for one month, and then he is instructed to increase by 10%. For example, if an individual is able to actively swim in a pool for half an hour, then one-half hour would be his maximum exercise capability. He would begin swimming just six minutes per session three to four times per week for a month before increasing the amount of time actively swimming to nine minutes three to four times per week for another month. Then he would increase by 10% once again so that he was actively swimming 12 minutes per session three to four times per week for another month, and so on. After three to four months, our patients have reported that they feel an increase in their general stamina or endurance.

Alternatively, if an arm ergometer or exercise bicycle is used, the same basic principle can be utilized, calculating distance pedaled or time spent actively pedaling. The individual begins his aerobic or non-fatiguing general conditioning exercise program at 20% of maximum exercise capability three to four times per week for one month before increasing the distance by 10%. He continues with that level of activity for another month before increasing by another 10%, so that he is exercising at 40% of maximum exercise capability.

For example, if an individual is able to pedal an exercise

bicycle for one mile or is able to actively pedal the bicycle for up to 20 minutes, then that is his maximum exercise capability. He is instructed to begin his exercise program at one-fifth of a mile (or, if time is used, then four minutes is the beginning exercise time). This is repeated three to four times per week for a month before increasing the distance to one-third of a mile or six minutes. Our patients are encouraged to maintain that for an additional month before increasing by another 10%, and so on.

Individuals are cautioned to stop if they become fatigued during their exercise program, or if they experience pain or aches in their muscles. Most polio survivors are able to continue increasing their exercise program to nearly the maximum exercise capability, though it clearly would take a full nine months if this program were strictly followed. Conditioning or aerobic exercise at this submaximal level allows the individual to regain a healthier sense of stamina without damaging delicate old motor units.

It is imperative to incorporate the concept of pacing and spacing within the non-fatiguing general conditioning exercise program, meaning that rests are to be taken every few minutes.

The 20% rule is sometimes also applied to polio survivors when they are given instructions in a home flexibility and stretching program so they do not exercise too vigorously.

This exercise program can be modified with the supervision of a physical therapist, depending on the progress made by the polio survivor. This program may not eliminate fatigue, but we have found it effective for those who have a significant element of deconditioning contributing to their sense of fatigue.

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BASIC BEGINNING EXERCISE FOR POLIO SURVIVORS AND MORE

"Exercise admonitions: Take these exercises to your doctor and ask your doctor if it is all right for you to complete this routine. Do not exercise within one hour of a meal (before or after). Do not exercise within two hours of the time you plan to go to bed. Do not continue to exercise if you feel very tired or are unable to talk easily. Remember that if you are more fatigued after exercises you should not increase the frequency of exercises and you may want to break up the exercises so that you complete five of the exercises in the morning and five in the afternoon. Stop any exercise that causes any sharp pain. If possible, exercise when someone else is close by. Start by completing the exercises once daily. After two weeks of daily exercises, and depending on how tired you are after exercising, you may increase the exercises to twice daily." David Guy, MS, CPT USA (ret). Guy is a retired physical therapist who has worked in multiple settings from the Army to universities. He



has worked with polio survivors throughout his career. He now helps out with a polio support group in Arizona.

Beginning Exercise

1. Seated on a chair with arms, place your hands on your knees, then, simultaneously, raise your arms overhead and breathe in deeply. Lower your arms and exhale. Complete five repetitions.
2. Seated in a chair with arms, stretch your arms straight in front of you and then, slowly twist your arms and your body to the left and then, to the right. Complete five repetitions.
3. Seated in a chair with arms, grasp the arm rests, lean forward and pushing down on your hands on the chair arms, try to lift your bottom off the chair. Complete five repetitions.
4. Seated in a chair with arms, lean back into the chair and try to lift your right knee up. Lower the right knee and do the same with the left knee. Complete five repetitions with each leg.
5. Seated in a chair with arms, lean back and try to straighten out your right knee and lift your foot up as high as you can. Lower the right foot and do the same exercise with your left leg. Complete five repetitions with each leg.
6. Rest for 20 to 30 minutes after completing the exercises.

Additional Exercises

1. Lying on your bed, lift one leg straight up as you are able without bending the knee
2. Lying on your bed, place a small rolled towel behind your knee and then try to straighten that knee.
3. Lying on your bed, bend both legs and place your feet so that they are flat on the bed. Reach with your hands up toward your knees and lift your head and shoulders.
4. Lying on your bed, bend both legs and place your feet so that they are flat on the bed. Move both knees as far as possible to the left and then to the right as far as possible.
5. Lying on your bed, bend both legs and place your feet so that they are flat on the bed. Reach with your hands up toward the left and twist your body to the left also. Do the same to the right.
6. Turn over and lie on your stomach. Put your arms at your sides and try to lift your head and shoulders up as far as possible.
7. Seated, pick up your leg and hold it up and then try to move your foot to the left and then to the right. If possible, keep your knee up without holding it up.
8. Seated move your knees apart and then together but keep your feet together and in place as you move your knees.
9. Standing and holding onto a counter, move the right leg as far as possible to the right. Make sure that the toes are pointing straight forward throughout the exercise. Do the same with the left leg.
10. Standing and holding onto a counter, bend both knees about 30 degrees and no further. Straighten both knees.

Do all the exercises above 20 times, twice daily if you can. Remember to not get fatigued.

In addition, try to lie on your stomach and up on your elbows. Keep your hips down and in contact with the bed. Stay in this position for 20 minutes.

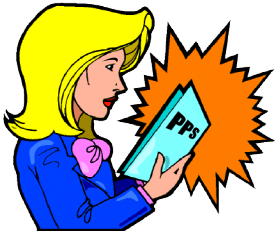
Flexibility and Breathing Exercises for Polio Survivors

1. Seated, reach first as far forward as possible and, then, simultaneously exhale and bend forward as far as possible. After bending forward, simultaneously reach up overhead and breathe in as deeply as possible. Very slowly complete 5 repetitions.
2. Seated, reach up toward the ceiling and simultaneously inhale as deeply as possible. Exhale and bend to the right as far as you can. Straighten up again inhaling as you reach up. Then, exhale and bend to the left as far as possible. Complete three repetitions resting between each repetition.
3. Place both hands on your right knee. Keeping your hands together and elbows straight, reach with both hands up and out to the left side twisting your body to the left as far as possible. Lower your hands to your left knee and then, complete the exercise moving to the right. Complete three repetitions resting between each repetition.
4. Fold a tissue in half and then in thirds. Grasp the tissue at the top and hold the tissue three inches in front of the mouth. Purse your lips and blow out as hard as possible against the tissue attempting to bend the tissue 90 degrees and to keep it bent at 90 degrees for a count of six. Complete 5 repetitions of this exercise and then rest for several minutes.
5. Place your hands below the ribs across the upper abdomen. Simultaneously exhale and compress the upper abdomen. Then, breathe in as deeply as possible and attempt to force your hands out. Release pressure on your abdomen as the downward movement of the diaphragm is felt. Complete 5 repetitions and rest for several minutes.
6. Seated, fold your arms across your chest. Rotate your body to the right as far as possible and then to the left. Complete 10 repetitions.
7. Seated, pull your chin straight back and flatten the back of your neck pulling the ears directly over the shoulder joints. Relax after each repetition. Complete 10 repetitions.
8. Seated, hold both arms straight ahead with the elbows slightly bent. Pinch your shoulder blades together toward your spine. Hold for a count of five and then relax. Complete 10 repetitions.
9. Sit in a chair with arms. Place both your hands on the arms of the chair and holding the head, neck and trunk still, straighten your arms and lift your buttocks 2-3 inches above the seat of the chair. Relax. Complete 5 repetitions.
10. Seated, try to blow up a balloon.



Reprinted with Permission. Yarnell, MD, Stanley K., "NON-FATIGUING GENERAL CONDITIONING EXERCISE PROGRAM (THE 20% RULE) BASIC BEGINNING EXERCISE FOR POLIO SURVIVORS AND MORE," *Polio Place*, Post-Polio Health International, 29 Aug 2013, <<http://polioplac.org/living-with-polio/sample-exercises>>.

Reprinted with Permission. "BASIC BEGINNING EXERCISE FOR POLIO SURVIVORS AND MORE," *Polio Place*, Post-Polio Health International, 29 Aug 2013, <<http://polioplac.org/living-with-polio/sample-exercises>>.



Understanding Post-Polio Syndrome

Post-polio syndrome (PPS) is a condition that affects polio survivors years after they've recovered from their initial bout with the disease. An interval of 30 to 40 years usually elapses before the first PPS symptoms occur, but intervals as short as eight years and as long as 71 years have been documented. Modern rehabilitation may restore individuals with post-polio to their regular level of functioning; it may also require that they return to or begin using braces, crutches, canes, wheelchairs and a variety of adaptive equipment.

Weakness is the general symptom of post-polio syndrome. Muscle strength decreases when the nerve supply to the muscle is reduced. Symptoms can appear in the muscles that were affected at the time polio was contracted or in previously unaffected areas. Most new pain problems in polio survivors result from repetitive strain injuries to weakened muscle fibers and muscular tissues.

Understand

- Post-polio syndrome is not a recurrence of the virus.
- The rest necessary to resolve pain and inflammation often leads to further weakness and atrophy. Thus, a vicious cycle of increasing weakness, increasing pain and increasing disability can result.
- Shrinking of muscle size and decreasing strength occurs very slowly, at a rate of 1 percent of muscle strength per year.
- Individuals with post-polio have less muscle reserve and may need more time to resume normal activity after surgery or severe illness.
- Family and friends should be supportive of lifestyle changes, accept the survivor's physical limitations and assist polio survivors in taking responsibility for their own care.

Causes

Aging of the previously damaged muscles and limbs and chronic strain of muscles whose strength was overestimated. (Post-polio survivors who consistently use remaining muscles at high intensity for many years are likely to develop Progressive Post-Polio Muscular Atrophy).

Medical problems unrelated to polio which may cause progression of post-polio weakness and lead to new symptoms.

Additional factors which contribute to late muscle deterioration include:

- Normal age-related loss of motor nerve cells
- Environmental toxins which can hasten nerve degeneration

- Health problems, such as a heart condition, pneumonia, arthritis or a fracture
- Disuse atrophy, resulting from an age-related reduction in activity

Symptoms

- Unaccustomed muscle fatigue
- Significant fatigue after moderate exercise or activity
- Rapid muscle tiring or feelings of total body exhaustion
- Joint and/or muscle pain
- Arthritis in the back, wrist, hand and in joints of lower extremities; degenerative arthritis of the shoulder and carpal tunnel from canes and crutches
- Osteoarthritis of spine and peripheral joints, scoliosis, bursitis, tendonitis, myofascial pain syndrome, foot and toe deformities, and chronic pain from strain to back and neck muscles.
- Osteoporosis of spine and long bones. (Long bone fractures may occur with minimal stress.)
- Pain in the spine, lower back and upper limbs
- A "flu-like" aching in muscles
- Muscle weakness and/or loss of muscle use
- New muscle weakness, both in those muscles originally affected and those unaffected, increased weakness or pain, generalized fatigue, post-exercise weakness and/or pain, muscle twitching or muscle spasms. (These may be signs of overuse before lasting muscle weakness occurs.)
- Respiratory problems/breathing difficulties
- Morning headache or confusion, difficulty swallowing, shallow breathing patterns and breathlessness while speaking (Deteriorating respiratory muscles may require breathing aids.)
- Sleep problems such as insomnia, restless sleep, nightmares, sleep apnea (which can result from severe respiratory impairments)

Living with Post-Polio Syndrome

Since some medical professionals do not recognize the symptoms of PPS, it is very important that a general medical evaluation be done to exclude other conditions which may mimic post-polio syndrome.

Further diagnosis and treatment by a specialist may then be necessary. Specialists dealing with post-polio syndrome include neurologists, pulmonologists, physiatrists and orthopedists.

Managing Post-Polio Syndrome

- Pain and inflammation of muscles, joints and supportive tissues must be reduced through traditional therapy techniques.
- Any activity which is the source of repeated injury, muscle strain, cramping or persistent fatigue should be avoided.
- Polio survivors should exercise on a regular basis,

including flexibility, strengthening and conditioning exercises into their regimen. Warm-water pools are especially helpful.

- Corrective shoes, canes, crutches and appropriate lower extremity bracing help prevent arthritis in the back and joints of the lower extremities.
- Light leg braces, wide grips on wrists and hands and maintaining reasonable body weight reduce the danger of arthritis.
- Severely affected polio survivors should use wheelchairs or electric carts when traveling long distances.
- Psychological stress from the development of new impairments and disabilities is an important and real problem for polio survivors who experience the late effects of polio. Depression and anxiety may be secondary effects. Support groups can be helpful.

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"Understanding Post-Polio Syndrome." <<http://www.easterseals.com/explore-resources/facts-about-disability/understanding-post-polio.html>>. Easter Seals, Inc., Web. 28 Aug. 2013.

Myths and Facts About People with Disabilities



Everybody's fighting some kind of stereotype, and people with disabilities are no exception. The difference is that barriers people with disabilities face begin with people's attitudes – attitudes often rooted in misinformation and misunderstandings about what it's like to live with a disability.

Myth 1: People with disabilities are brave and courageous.

Fact: Adjusting to a disability requires adapting to a lifestyle, not bravery and courage.

Myth 2: All persons who use wheelchairs are chronically ill or sickly.

Fact: The association between wheelchair use and illness may have evolved through hospitals using wheelchairs to transport sick people. A person may use a wheelchair for a variety of reasons, none of which may have anything to do with lingering illness.

Myth 3: Wheelchair use is confining; people who use wheelchairs are "wheelchair-bound."

Fact: A wheelchair, like a bicycle or an automobile, is a personal assistive device that enables someone to get around.

Myth 4: All persons with hearing disabilities can read lips.

Fact: Lip-reading skills vary among people who use them and are never entirely reliable.

Myth 5: People who are blind acquire a "sixth sense."

Fact: Although most people who are blind develop their remaining senses more fully, they do not have a "sixth sense."

Myth 6: People with disabilities are more comfortable with "their own kind."

Fact: In the past, grouping people with disabilities in separate schools and institutions reinforced this misconception. Today, many people with disabilities take advantage of new opportunities to join mainstream society.

Myth 7: Non-disabled people are obligated to "take care of" people with disabilities.

Fact: Anyone may offer assistance, but most people with disabilities prefer to be responsible for themselves.

Myth 8: Curious children should never ask people about their disabilities.

Fact: Many children have a natural, uninhibited curiosity and may ask questions that some adults consider embarrassing. But scolding curious children may make them think having a disability is "wrong" or "bad." Most people with disabilities won't mind answering a child's question.

Myth 9: The lives of people with disabilities are totally different than the lives of people without disabilities.

Fact: People with disabilities go to school, get married, work, have families, do laundry, grocery shop, laugh, cry, pay taxes, get angry, have prejudices, vote, plan and dream like everyone else.

Myth 10: It is all right for people without disabilities to park in accessible parking spaces, if only for a few minutes.

Fact: Because accessible parking spaces are designed and situated to meet the needs of people who have disabilities, these spaces should only be used by people who need them.

Myth 11: Most people with disabilities cannot have sexual relationships.

Fact: Anyone can have a sexual relationship by adapting the sexual activity. People with disabilities can have children naturally or through adoption. People with disabilities, like other people, are sexual beings.

Myth 12: People with disabilities always need help.

Fact: Many people with disabilities are independent and capable of giving help. If you would like to help someone with a disability, ask if he or she needs it before you act.

Myth 13: There is nothing one person can do to help eliminate the barriers confronting people with disabilities.

Fact: Everyone can contribute to change. You can help remove barriers by:

- Understanding the need for accessible parking and leaving it for those who need it
- Encouraging participation of people with disabilities in community activities by using accessible meeting and event sites
- Understanding children's curiosity about disabilities

and people who have them

- Advocating a barrier-free environment
- Speaking up when negative words or phrases are used about disability
- Writing producers and editors a note of support when they portray someone with a disability as a "regular person" in the media
- Accepting people with disabilities as individuals capable of the same needs and feelings as yourself, and hiring qualified disabled persons whenever possible

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"Myths and Facts About People with Disabilities."
<<http://www.easterseals.com/explore-resources/facts-about-disability/myths-facts.html>>. Easter Seals, Inc., Web. 28 Aug. 2013.



In Memory

September 11, 2001-2013

Good News

Dorinda and I visited Janet yesterday and were so happy to see how well she is doing. She has been off the ventilator for six weeks! She is excited about returning to River's Edge and resuming her life. Lots of folks from River's Edge surprised her on her birthday with a visit. Janet talked the whole time we were there, sharing her experiences and plans for the future. She has to be weaned off the trach and it has to be closed before she can come back to her home, but the progress she has made so far is proof that she can accomplish it. She now has a cell phone and will be making some calls to friends, but asks that no one call her because she is unable to answer it unless she is using the passy muir trach which enables her to talk.

Sandra Bath

From an e-mail from Sandra Bath to Jim Veccia, 14 July, 2013.

I visited with Janet yesterday in Statesboro. She has cut her hair and looks like her ole self again. She's been off the ventilator since June 6th and is doing well. She has trouble using her voice and mostly "talked" with me through written notes. She loves mail!

Marty Foxx



Janet DiClaudio
Eagle Health & Rehab
Room B-32
405 South College Street
Statesboro, GA 30458-5409

From an e-mail from Marty Foxx to Jim Veccia, 08 Aug, 2013.

The articles, seminars, thoughts, ideas and suggestions mentioned in this newsletter are provided as a public service and do not express or imply endorsement by CEPESA, CEPESA's THE LIGHTHOUSE or its editors. They are for your information only. Consult with your doctor or health care provider before beginning any new medication, product or program. CEPESA, CEPESA's THE LIGHTHOUSE and its editors do not assume any responsibility for an individual's actions.

Happy Birthday



September	October
Anna White - 1	Carlos Clas - 1
James F. Smith - 3	Billy Ray Washington - 3
Cheryl Brackin - 6	Mildred Roberts - 4
Robbie White - 6	Eileen Boyle - 5
Danny Jenkins - 10	Dan Shehan - 6
Ed Luck - 11	Hattie Evensen - 7
Marge Lampke - 15	Rev. Edward Ellis - 11
Betty Johnson - 16	Skeet Varnadoe - 15
Patrina Johnson - 19	Michael Dunnermann - 16
Richard Hall - 24	Linda Munn Graham - 19
Dot Parkhurst - 27	Adrienne Stallworth - 31

Member Concerns

Sandra Bath, Wakil Carter (son of Ruth Parham), Janet DiClaudio, Hattie Evensen, Archie Ivey, Marge Lampke, Ed Luck, Sally Luck, Delores McIntyre, Harriett Merritt & Charles Sexton (son-in-law of Nancy & Steve Hess)
Please keep these members in your prayers.

Condolences



CEPSA would like to offer condolences to Richard and Linda Graham and their family on the loss of Richard's brother Wes. Richard was an incredible brother and support for Wes and his family. Richard was always at Wes's side. Please keep them in your thoughts and prayers.

Our condolences and support to Cheryl Brackin, her sister Sheila Tillman and their family. They have had a tremendous amount of personal loss this summer. Cheryl's brother-in-law Bill Tillman passed away on July 13, 2013. On that day Cheryl wrote, "My brother-in-law Bill Tillman died today at 1:20pm at their home in Baxley under Hospice care. Please remember my sister Sheila, my nephew Brad, and Bill's sister and two brothers in your thoughts and prayers. I was blessed to be with Bill and the family when he left us."

In June Cheryl's childhood friend Michael O'Quinn, who was the uncle of her niece and nephew, passed away. In August, Cheryl and Sheila's cousin Jane Brackin Parker passed away in Florida after a 4 year battle with cancer. Together they attended the funeral. Our prayers and thoughts are with Cheryl and her family.

We have had our own losses this summer. We had the loss of Carlos's brother Tommy. Tommy battled dementia and had complications from diabetes before his tragic death in July. He never recovered from all the injuries from his "accident." In August, my uncle Gil passed away after a long stay in the

hospital. He was my mother's oldest brother. He will be missed by us always.

We would like to thank everyone for the cards, calls and well wishes for our family. Your support means the world to us. We cherish all your prayers.

Carlos & Wanda Clas

Prayer Requests

Dear CEPSA family,

Charles Sexton, 40-year-old son-in-law of Nancy & Steve Hess of Statesboro, needs our prayers. He has a tumor between his esophagus and stomach. Charleston doctors did not come up with anything definitive and have referred him to Mayo Jacksonville, where two surgeons are familiar with this type of tumor. Charles lives in Beaufort and is married to the Hesses' daughter Stephanie. They have two sons, ages 8 yrs. and 5 yrs. Please remember Charles and the family in your thoughts and prayers. I will stay in touch with Nancy to learn when he will go to Mayo and what type of treatment is being recommended.

Cheryl

From an e-mail from Cheryl Brackin to Jim Veccia, 23 July, 2013.

Sally & Ed need our prayers...

Ed and I surely do miss you all. There is no support group here and I have found that leaves a big hole in my life. I have gotten so much weaker this year and would really benefit by having a support group. I can not drive any more because my right arm has become very weak and also both legs. And of course pain is always an issue. Sure do miss Dr. Cramer. Ed is a great caregiver but we don't know how much longer he will be able to do this as he was diagnosed with dementia this spring. The meds are helping for now but it is a take one day at a time existence. My regards to all the CEPSA members. Receiving the wonderful, informative newsletter is a real blessing.

Sally

From an e-mail from Sally Luck to Jim Veccia, 30 Aug, 2013.

Congratulations

Hey you all,

We are moving to Texas to be closer to family. We have purchased a home in the same subdivision as our daughter. Will miss all of you and would like to keep in contact.

Moving truck comes July 19th. Leaving soon after that. Thank you for all your help and prayers. God is so good!

Love ya all,

Larry and Charlotte



From an e-mail from Charlotte Richter forwarded to Jim Veccia, 10 July, 2013.

We are so sad to see Charlotte and Larry go, but we know that they are very excited to be nearer to their family. They have been an asset to CEPSA and great friends to us all. We wish them health and happiness in their new home.



Living Independence for Everyone, Inc. (LIFE) commemorated the 23rd anniversary of the

signing of the Americans with Disabilities Act on July 26 with an ice cream social at the office. Lorraine Frew and Cheryl Brackin attended and represented CEPSA. They participated in a discussion of our rights under the ADA along with other attendees.

From an e-mail from Cheryl Brackin to Wanda Clas, 24 Aug, 2013



On July 29, 2013, Delores McIntyre married her long time friend, Wes Shephard. Congratulations to them and best wishes for their future together.

"Now join your hands, and with your hands your hearts."

-William Shakespeare



A big thank you to Dan Shehan for his service on the Savannah-Chatham Council on Disability Issues. He was appointed in 2007 by the Savannah City Council and reappointed for another two year term in 2009. In 2011 Dan was appointed by the Chatham County Commission to a five year term; however, he decided to retire August 30 of this year due his increasing fatigue. He always kept CEPSA members informed about SCCDI information and events. Congratulations on a job well done. Time to rest!

"It was due to CEPSA's Historic District Navigational Guide for Scooter and Wheelchair Users published in 2007 that I was asked to serve on SCCDI. Thank you, CEPSA." -Dan

Thank You

Dear CEPSA Members,

I appreciate your prayers, condolence cards, and calls during the illness and death of my brother-in-law Bill Tillman. My family and I sincerely thank you for your caring and kindness.

Love and Blessings,

Cheryl Brackin

From an e-mail from Cheryl Brackin to Wanda Clas, 24 Aug, 2013

Quote of the Month



"I enjoy the spring more than the autumn now. One does, I think, as one gets older."

-Virginia Woolf, *Jacob's Room*

LIFE's Annual Wheelchair Cleaning Event

September 14

9:30-12:30

5105 Paulsen Street

Suite 143-B

Executive Court

Let's have some fun!



Enjoy entertainment, snacks, free blood pressure checks and great information while they clean and perform a free basic inspection on your wheelchair or scooter!

Manual WC's may remain a bit damp, Please bring a towel.


Call 912-920-2414 for more info or to RSVP

*Teleride will provide free transportation to individuals who are registered with them.



Coastal Empire Polio Survivors Assoc., Inc.
 23 East 61st Street, Savannah, GA 31405
 GA (912) 355-1221 • SC (843) 837-1230
 E-mail: CEP5A05@msn.com
 www.coastalempirepoliosurvivors.org

Shining Light on Post-Polio Health

CEPSA's next meeting is on
 Saturday,
 September 28, 2013 
 10:30 AM
 at The Exchange on Waters
 6710 Waters Avenue
 Savannah, GA 31406

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 Other
- * 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 _____

Address _____

City _____ State _____ Zip _____

Phone _____ E-mail _____

Are you a relative or friend of a CEPSA member? _____

Name of member

Thank you for your support and encouragement.