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

February, 2013 Newsletter

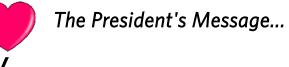
www.coastalempirepoliosurvivors.org

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2-3

4-7

12



What a great group we had for our first meeting of 2013!! It was good to see all of you. We offer sincere thanks to Harvey Varnadoe for completing his excellent presentation on pain management. Our new meeting location at The Exchange on Waters received several favorable reviews.

Our beloved Janet DiClaudio now is at Eagle Health and Rehabilitation in Statesboro. She has fought valiantly over many weeks. Please stay in touch with her and visit when you can.

"Don't ever forget me," said Sophie, my then three-year-old niece. Her Mommy Lorie wrote the message on a treasured card they sent to me. As I recently reviewed CEPSA's website, Sophie's words came to me. Somehow those words send the message of this group and polio survivors everywhere. We want our communities and the world to know our history, our stories. To know that our journeys have been different than those of non-polios. To know that we survived and overcame a dreaded disease. To know that the polio epidemics changed rehabilitation of the disabled in developed countries. To know that the second battle with polio (post-polio syndrome), for some of us, came in the prime of our adult lives. To hear the words of own stories and read them in our newsletter and on the web. To know that we have made a difference in the lives of many with our support and compassion. Present and future generations can learn from our challenges and our will to survive. We mourn those members no longer with us; we will never forget them. People live on in memories and stories. We want no pity, ever. Only remembrance.

Cheryl Brackin, President



### Presidents' Day (February 18, 2013)

Presidents' Day is an American holiday celebrated on the third Monday in February. Originally established in 1885 in recognition of President George Washington, it is still officially called "Washington's Birthday" by the federal government. Traditionally celebrated on

February 22—Washington's actual day of birth—the holiday became popularly known as Presidents' Day after it was moved as part of 1971's Uniform Monday Holiday Act, an attempt to create more three-day weekends for the nation's workers. While several states still have individual holidays honoring the birthdays of Washington, Abraham Lincoln and other figures, Presidents' Day is now popularly viewed as a day to celebrate all U.S. presidents past and present.

Presidents' Day. (2013). The History Channel website. Retrieved 12:59, February 12, 2013, from http://www.history.com/topics/presidents-day.

# What's Inside THE LIGHTHOUSE:

### **CEPSA Business**

-General Meeting Minutes -JOIN US -Our February Program -Dues -Pain Management: Part 2 Program with Harvey Varnadoe

#### Articles

-From Henry's Desk by Henry Holland **Polio Spouses** -Worth Their Weight in Gold!!! by Jim Veccia -Impact of PPS on a Polio Partner by Dave Van Aken -True Answers for Friends and Family by Dr. Richard Bruno

#### Announcements 8-9

-Birthdays -A Note to Janet -Quote of the Month -Member Concerns -For Your Information Georgia Center for Nonprofits Social Security News: PAPER CHECKS WILL END Prescription Drug Drop-off Box -LIFE's Valentine's Day Social

### Articles

9-11 -SHAKING SALT, SUGAR FROM YOUR DIET.... Consumer Reports Magazine -Inflammation And Pain

Research by Diane Davis -Elevated Toilet Seat Photos Courtesy of Linda Rosario Clas

#### Contributions -Contributions Form



Next Meeting Saturday, February 23, 2013 10:30 AM

## Coastal Empire Polio Survivors Association, Inc. General Meeting Minutes for January 26, 2013 Location: Exchange Restaurant

President Cheryl Brackin called the meeting to order at 10:38 am and then welcomed back Lorraine Frew, Susan & Paul Pineo, Delores McCall and Joan & Alan Page. Joyce Taylor, friend of Delores McCall also was welcomed.

Lorraine Frew led the Pledge of Allegiance.

The inspiration was given by Cheryl Brackin who read a poem "A Song of Gladness" by James William Foley.

Program: Harvey Varnadoe, RN and polio survivor, continued his presentation on "Pain Management" taken from the twoday seminar he attended. It was very informative, and we all had an opportunity to ask questions about how to treat pain. Harvey stressed the importance of making sure we inform all our doctors of our prescribed medications, due to the possibility of adverse interactions. We should include any over-the-counter drugs we take. We learned about how acute illness can present with a sudden onset of pain; chronic illness can be accompanied by long-term pain. Elevated white blood cell counts and leg cramps commonly occur in polio survivors. We were advised to use caution when telling a doctor we are allergic to a medication. We should not get side effects confused with allergic reactions. This distinction can result in our being unable to receive the medication we need in an emergency situation. Be sure you discuss with your doctor prior to putting this information in your records.

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 Marty Foxx and approved as presented. Marty highlighted the new CEPSA record in 2012 of having 62 dues-paying members.

Skidaway Rotary Project: Lorraine reported on the progress of the bathroom modification to install a walk-in shower in her home. Tom stated that we owe many thanks to the Rotary and the Balfour Company, which is donating their time and the materials. Harvey and Tom plan to contact the Brunswick Rotary to request their assistance with projects for CEPSA members in that area. The Rotary International Conference will be held in Atlanta in 2016. It has been requested that we loan our iron lung for the event.

Care Team: Care team leaders gave their reports.

Announcements: Cheryl reported that LIFE is holding a Valentine's Day open house February 14<sup>th</sup>, 1-3 pm. CEPSA members are welcome to attend. Cheryl is making some progress on setting up a meeting to speak with the Savannah postmaster about our obtaining free mailing privileges for our newsletter.

The meeting was adjourned at 12:44 pm.

Respectfully submitted, Michael Dunnermann, Vice-President/Secretary

Attendance: Cheryl Brackin, Wanda Clas and Carlos Clas, Diane Davis, Esther Simmons, Della Simmons, Michael & Terri Dunnermann, Harvey Varnadoe, Delores McCall, Joyce Taylor, Tom Schendorf, Marty Foxx, Harvey Varnadoe, Ross & Penny Smith, Lavonne Calandra, Betty Goff, Sissy Morel, Nancy & Steve Hess, Dan Shehan, Lorraine Frew, Barry Turner, Marge & Jim Lampke, Brenda Mills, Ann Chance, Sandra Bath, Susan & Paul Pineo, Joan & Alan Page, Charlotte & Larry Richter.

### \*\*\*\*\* JOIN US \*\*\*\*\*

Our January meeting was jam packed with CEPSA members, their family members and friends. It was great to see such a large turnout. We need to continue "showing-up" in large numbers. It is encouraging to see those who have not been able to come to the meetings regularly. We are so happy to see you and glad you came. Please continue to attend; you are an inspiration to those that are finding it difficult to join us. Let's see if we can raise the attendance with every meeting!

\*\*\*<u>PLEASE ENTER THE MEETING ROOM THROUGH</u> <u>THE RIGHT SIDE OF THE RESTAURANT.</u>\*\*\*

> CEPSA's **new meeting place** is at: **The Exchange** (Restaurant) **on Waters**, 6710 Waters Avenue Savannah, GA 31406

# Our February Program

Our February Program is still in the works. We have a couple of people that would be great as speakers, but they are still tentative. We are crossing our fingers that they will be able to share their knowledge with us at the next meeting or perhaps in the near future. If you know someone that might like to be one of our Program Speakers, please see Cheryl Brackin. All suggestions are welcomed.

Voluntary Dues of \$15.00 may be paid to: Marty Foxx 23 East 61<sup>st</sup> Street Savannah, GA 31405 Please try to make your payment this month, either at our next meeting or else by mail. <u>Thank you.</u>

## Pain Management:Part 2 Program January 26, 2013 with Harvey Varnadoe, RN

Harvey Varnadoe, RN, CEPSA member and polio survivor, concluded his presentation of "Pain Management" from our October, 2012 meeting program.



Some previous points were revisited and new points were discussed. Below are a few of the points that Harvey covered in "Pain Management: Part 2."

- 1. Pain is usually the first indicator that something is going on in the body that is not quite right.
- 2. Pain meds injected "above" an injury can be more helpful that on the injury.
- 3. Pain is usually measured on a scale of 1-10--1 being "something is not quite right," and 10 describing "excruciating pain" that is enough to cause you to pass out.
- 4. There are different protocols for dealing with different kinds of pain in the ER. Chest pain, for example, requires a different protocol than pain from kidney stones.
- 5. About 20% of women over 60 having lower abdominal pain may be having a heart attack.
- 6. Having pain in the chest area to left arm or left jaw is common to men having a heart attack, but not always to women. In women, one of the common areas is between the shoulder blades.
- 7. If you are having chest pain, you may be treated with a "GI cocktail" first. It is a "cocktail" of Lidocaine and other medications that work well in this situation. This is a recommendation not a protocol. Chest pain protocol will continue while "GI cocktail" is being given.
- 8. Sometimes finding the source of pain can take several years.
- 9. Pain usually stems from inflammation. Chronic inflammation can lead to heart attacks, strokes, dementia and cancer.
- 10. Fish oil, found in Omega 3's, can be helpful with heart health.
- 11. A normal white blood cell count is 4,500-10,000 white blood cells per micro-liter. If the white blood cell count is high for an extended period of time, it is an indicator of chronic inflammation. It can also be an indicator of Post-Polio Syndrome.
- 12. If you have acute pain and lose bladder or bowel control, go to the ER **as soon as possible.**

- 13. PPSers can have limbs of different lengths that can cause pain and even Carpel Tunnel Syndrome.
- 14. Neurontin is a non-narcotic that can be used to control many chronic nerve pain type disorders. If you are using this drug, do not stop using it suddenly. Taper it down under doctor's supervision. Check with your doctor before stopping this medication.
- 15. Pregabalin may be given to a patient with pain to help them sleep.
- 16. ALL drugs have side effects...even aspirin.
- 17. For about 20 years, aspirin was said to stop macular degeneration. Now they say it can cause it.
- 18. Aspirin takes away the "stickiness" from your platelets, it doesn't "thin" your blood.
- 19. Take 2-4 baby aspirin if you are having signs of a heart attack and let them dissolve under your tongue. You can chew them, but don't swallow them.
- 20. Enteric coatings on meds are there so that they do not dissolve in the stomach. They dissolve in the intestines to help prevent bleeding in the stomach.
- 21. 5% Lidocaine patches are great for back pain because Lidocaine is a numbing agent. They are also very good for compression fractures, especially in older people. They have very few side effects. They can be cut and fit on other joints to relieve pain.
- 22. Steroids injected into a painful joint are helpful in reducing inflammation and, therefore, relieving the pain.
- 23. Sickle Cell Anemia is one of the most painful diseases there is. The blood clots and becomes very painful. The blood has to be "diluted" to ease the pain.
- 24. Ultram or Tramadol are also commonly used for pain relief. They work well, like Ibuprofen when treating pain.
- 25. Tell your doctor about ALL the medications you are taking, especially if you have high blood pressure.

#### 26. KNOW THE DIFFERENCE:

**An allergy**- a hypersensitivity to a substance that can include breaking out in hives, itching, swelling and also particularly, difficulty breathing because of throat swelling.

A side effect- a secondary, unwanted effect from a drug or therapy regimen , such as nausea or vomiting.

27. Pain itself can become an addiction. Pain can be treated by other methods of relief, not just medications. You might want to try massage therapy, acupuncture, heat or even imagery where you learn to concentrate on "something else" besides the pain. This method is used widely in childbirth and can be very effective in treating pain.

Thank You, Harvey, for a very informative and professional presentation.

# From Henry's Desk by Henry Holland Polio Spouses



Eleanor Roosevelt is probably the most famous polio spouse in American history. She was born into an aristocratic family on November 7, 1884. However, emotional losses and low self-esteem plagued her developmental years. She was the oldest child and only daughter of Elliott Roosevelt, President Theodore Roosevelt's brother, and his beautiful and vivacious wife, Anna Livingston Ludlow Hall. At age two and a half, she was crossing the Atlantic with her parents when their ship was involved in a collision. The terror of being lowered from on high to a lifeboat left her with a fear of heights and the water. As a young child, her mother called her "Granny" because she was so serious and mature. When she was six, her mother said, "You have no looks, so see to it that you have good manners." As a result, Eleanor tried to be dutiful, compliant, obedient, responsible, and useful, but she was also independent, goal directed, and willful.

Death left her an orphan by age eight. She had two younger brothers. One of them, Elliott, died at age four from scarlet fever. When she was eight, her mother died from diphtheria. Her father had a history of alcoholism and chronic depression. He was not awarded custody of Eleanor after her mother's death. Eleanor went to live with her maternal grandmother in Manhattan. Two years later, her father died from the consequences of alcoholism. She stayed with her grandmother for five years. During this time, she grew to be a tall, but rather awkward and self-conscious teenager. She was a loner and an outsider. At the age of fifteen, her grandmother sent her to the Allenswood boarding school in England. At this school, Eleanor came under the influence of the headmistress, Mademoiselle Marie Souvestre. This school was most progressive for the Victorian nineties. The daughters of England's more liberal leaders attended this school. Eleanor excelled at Allenswood for three years. She became more self confident, versatile, and a well loved young woman. At age eighteen, she returned to New York, involved herself in social work causes, made her debut in society at her grandmother's insistence, and soon met Franklin.

In August 1921, she became a polio spouse. During her husband's acute illness, she was his bedside nurse and performed many necessary duties such as attending to his urinary catherizations. Over the next several years, despite her mother in law's opposition, she kept the hope alive in Franklin's mind that he could return to politics. Franklin did become the four times elected President of the United States. During this time, Eleanor became his conscience, promoting progressive social reform. She became his legs and traveled throughout the world as his "ambassador of hope." She was a person ahead of her times. She was a feminist. She was compassionate and idealistic. She was a friend to the disenfranchised. She was an assertive and hopeful voice for the hungry, the unemployed, and African Americans. She became a writer, a teacher, lecturer, and voluntary ambassador.

When asked about her husband's polio, she would say his polio was a "blessing in disguise." Some had argued that FDR had always been a powerful and compassionate man; she believed that Franklin's struggle with polio "gave him a strength and courage he had not had before. He had to think out the fundamentals of living and learn the greatest of all lessons --- infinite patience and never ending persistence."

Eleanor appeared on the Edward R. Murrow TV Show, "This I Believe." In response to a question about her life, she stated, "You have to accept whatever comes, and the only important thing is that you meet it with courage and with the best you have to give."

In my opinion, Eleanor Roosevelt's perceptions as a polio spouse are astute and wise. As polio survivors, most of us learned long ago about the value of patience, persistence, and trying to think through the fundamentals of living. For many of us, polio brought a precocious understanding of the perils of life. If we did not learn and exercise these lessons years ago, we certainly need to exercise them now with the realities of Post-Polio Syndrome (PPS).

There are a number of polio spouses who are quite active in our post-polio support group. From my observation, these spouses fully represent individuals who have learned "to accept whatever comes" and have met adversity with "courage and the best they have to give." No marriage is all bliss and joy. The realities of polio and now PPS can stress the best of marriages. Based on the 1998 survey of our group, 70% of our members are married. 51% felt that the development of PPS had had some impact on their families. The changes that might result in a marriage relationship as a result of PPS can be adverse or, can be part of, the "for better or worse, in sickness and in health" definition of a committed marriage.

I think that polio spouses are often forgotten and overlooked heroes. For many of us, they are "gofers." They run errands, pick up things, and help with many details of daily living. They also get tired and moody, and have bodily aches and pains. Usually, they say "yes" more often than "no" to us, are our thoughtful personal advocates, and our loving protectors. Marriage relationships are traditionally complementary, as each spouse is expected to manage certain tasks toward the maintenance of a home and the raising of children. The invasion of PPS may alter the dynamics of that complement. As a consequence, the polio spouse may feel somewhat abandoned, needed more than loved, and less valued. This is more likely to occur when the PPSer is having greater difficulty accepting and adjusting to a life with PPS. When the PPSer is more anxious, fearful, depressed and uncommunicative, the polio spouse may be on the receiving end of irritability, complaining, and subtle rejection. Both marriage partners may well understand this process, but feel helpless in changing it. Meaningful communication is the key to working through the changes that have occurred and in establishing a new and lasting complementary relationship. If this level of communication is not possible, professional help may be an excellent next step.

As a first lady, Eleanor Roosevelt made a positive impact on the lives of many people. As a polio spouse, she must have felt the anger, fear, and uncertainty brought to their lives by her husband's polio. I feel that many polio spouses have felt and may still feel the anger, fear, and uncertainty that PPS has brought. There may be no brilliant dynamic psychotherapeutic models to resolve the realities of the impact of PPS on a marriage. Eleanor's advice is the best that I have heard.

"You have to accept whatever comes, and the only important thing is that you meet it with courage and with the best you have to give."

Originally published in "Polio Deja View", Central Virginia Post-Polio Support Group, Richmond, VA; 1999.

Worth Their Weight in Gold!!!

Several weeks ago I had a true reality check Gigi, my wife and caregiver, was taken to the hospital at three in the morning. That left me alone, to get myself over to the hospital to see her. With much difficulty, I made it there and back home. The next two days opened my eyes to how much I totally depend on her. The seemingly hundreds of tasks I cannot perform by myself, she does. Do I take advantage? Probably, Does she ever complain? Never. Since this incident I now question myself before asking for something. Can I, with a little effort, do it myself? If the answer is yes, then I proceed to do it. We must all give our caregivers the love and appreciation they deserve. Their God-given patience has made our lives livable. God has reserved a special place in heaven for these wonderful souls. Jim Veccia



I am not an expert. I am a husband and spouse. I am a Polio Partner, not a caregiver. There is a difference. A Partner is anyone who works to better someone's PPS situation. They can be a spouse, a brother/sister, a child or a friend...and I am a survivor. If necessary, I will adapt every day to our changing situation. When PPS came into our lives, we Partners faced a choice —fight or flight. We chose to stay and fight. But what are we fighting for? I am fighting to maintain my wife's quality of life, as well as our collective quality of life. My guess is we are each trying to accomplish the same thing.

The one thing I have found that is true about PPS is each survivor is different. As each survivor is different, then each of our situations is different. We do, however, face one common theme —coping with PPS involves a series of compromises. We must remain flexible and tolerant, as we must adjust to our Partner's ever-changing condition.

So, how are the Polio Partners impacted by PPS? I believe there are three main impacts on the Polio family — Financial, Physical, and Emotional.

# **Financial Impact**

It simply costs more to be disabled. Your family may have a loss in income. You may become the primary income producer for the family. Adaptive devices become necessary or required: braces, scooters, or power chairs. Modifications to your home could include ramps, grab bars, higher toilets, or even a new home. All create extra expense.

Traveling requires more forethought and planning. Depending on your situation, the impromptu "escape" trips may be a thing of the past. We trade in our sports cars for minivans to accommodate scooters or electric chairs. Public transportation offers even more challenges. Trains and plane service have advanced in dealing with the handicapped, but often have a way to go to become trouble-free.

## **Physical Impact**

We have all heard "Conserve to Preserve." Most Polio Survivors have had this preached to them repeatedly. We need to pay attention to this as well. We try to have our Partners conserve their muscles and adapt to new methods and devices. We should listen to our own advice and use technology, children, or friends to help share our increased load. We are aging as well and our own aches and pains will affect our ability to provide care for our Partners.

# **Emotional Impact**

Early on, when we are naïve or unknowledgeable, our expectations can be unrealistic. "If you do all of this, then you'll get better." "When you get better, we'll do this and that." We (some older Partners in one of our discussions) scared the "hell" out of a new Partner. As she admitted later, she expected her husband to beat this and they would carry on with the plans they had envisioned for themselves.

Anger, depression, anxiety. Our Partners thought they beat polio over 30 years ago, and now it has come back to haunt them. Their bodies are giving out, betraying them, and losing functionality. They lose "face" as they succumb to the adaptive devices in an effort to save what is left. Is it any wonder, they get angry at the world, and we, sometimes, bear the brunt of it?

We hurt as we watch our spouses suffer both emotionally and physically. At times, they lose their sense of self. As a culture, what we do for a living or where we volunteer often defines us. As our Spouses curtail this type activity, there is a sense of loss. This can trigger a sense of depression, which we, as Partners, try to cope with and ease our Partner out of it.

There is the physical side, or pain we watch our loved ones endure. We ache to be able to ease some of the pain they suffer. In most cases, we pick up extra chores so they don't have to do it.

We grieve over our futures. We — as couples or as individuals —had dreams and desires. While they do not have to be abandoned, they must be reevaluated.

<u>Mid to Late Stages</u>- As we grow older and more experienced with PPS, continual adjustments have become the norm. We must accept each situational change and move forward.

Fatigue periods can become common. These can add more anxiety, anger or depression for our "Type A" spouses. Polio fatigue crashes are real. Linda "crashed" in October of last year. For seven weeks, she was flat on her back. I adjusted. I did the housework, the laundry, and the cooking. Before October, my repartee in the kitchen was scrambled eggs or waffles. But, I provided Linda with hours of entertainment as she directed my efforts in the kitchen. We didn't starve and weren't poisoned, so I guess we did ok. [Guys —spend some time in the kitchen before you have to. It's a survival skill!]

The hardest part I find in being a Partner is watching the sometimes rapid decline of one of our Polio friends. We all know it may come. We hope and pray it won't. So, we nag and cajole our Partners and friends into behaving and conserving their abilities. A Partner friend confided that their biggest fear was not being physically able to care for their spouse. On the other side, their Survivor's biggest fear was becoming a burden on the Partner. Our fears are so much the same.

**Friends and Family-** Unfortunately, family and friends often judge our Partners by their appearance. What does fatigue and muscle weakness look like? Part, if not most, of the problem is that they look so normal. There is no disfigurement. They may have a slight limp, which has become more pronounced now, and they should always use their canes or crutches. Friends can't understand why they can't do this activity or that. They see them in their scooters, or using their canes doing the activities they choose. Why can't they do it all just like they used to?

Friends and family do not understand the Survivor must make choices each and every day about the most mundane things. My wife has a system she calls "energy presents." Every activity uses some energy presents. She has about 10 presents each day. So she monitors what she does, and tries not to exceed her 10 presents per day. But, sometimes she does, and she must take extra rest. And if she really blows it out, we both may enjoy the short term, but both of us will suffer the consequences.

# What Can We, as Partners, Do?

**Communicate,** communicate, and communicate! You and your Partner must communicate on your fears, your concerns, and your plans on how to move forward. Sometimes these discussions can become heated — prefer to think of them as passionate discussions (I think every relationship needs passion). The more emotional and honest, the better the understanding between both of you.

**<u>Educate Yourself</u>**—Knowledge is Power. Find out as much as you can about Polio and PPS. Apply what you learn to your situation.

Educate your family and friends. You need the help, and your Partner needs the support. If your family and friends don't get it, you have a choice —either continue to educate or drop off (another loss). It's your energy you are using, thus your choice.

Take Care of Yourself- Take charge of your life; do not let your Partner's disability or illness always take center stage. Be good to yourself, you deserve it. You are doing a very hard job. When people offer to help, let them. The task may not be done "the way you would," but it will be done. Grieve for your losses, and then begin dreaming new dreams. Trust your instincts. They will be right most of the time.

**Seek Support from Other Partners-** There is strength in knowing you are not alone. Many of the Survivors belong to a PPS support group. Do you, as a Partner, attend these meetings? Do other Partners attend? Grab some of the other Partners and go get some coffee while the PPSers meet. Encourage your support group to give you an opportunity to meet separately. Often a general discussion is all the agenda needed.

Reprinted from "Polio Deja View", Central Virginia Post-Polio Support Group, Richmond, VA; <a href="http://www.cvppsg.org/library/poliopartner.pdf">http://www.cvppsg.org/library/poliopartner.pdf</a>>.

# True Answers for Friends and Family By: Dr. Richard L. Bruno



#### What is Polio?

Polio (or poliomyelitis, infantile paralysis) is a disease caused by three viruses that enter the mouth, grow in the intestines and pass along the nerves into the brain and then the spinal cord. There are 1.63 million American polio survivors. (Editor's Note: This number is lower since this article originally was written.)

## What Damage Did The Polio Virus Do?

The polio viruses entered nerves in the brain and spinal cord and took over their metabolic factory, causing the nerves to stop working normally and just to produce polio virus. During this invasion, the infected nerves could not function and muscles in the arms, legs, chest, diaphragm and throat became weak or were paralyzed.

If someone had muscle weakness or paralysis, 90% of their motor nerves were affected by the polio virus and at least 50% were killed. The remaining nerves, although damaged, were able to work again and sent out sprouts (like extra telephone lines) to turn on the muscles that were orphaned when their nerves died.

## What are Post-Polio Sequelae (PPS)?

Post-Polio Sequelae (PPS) - new fatigue, muscle weakness, joint and muscle pain, cold intolerance and breathing and swallowing difficulty - are the sequel to having had polio and occur in as many as 80% of survivors of paralytic and non-paralytic polio.

### What Causes PPS?

PPS is caused by overuse abuse. Nerves that were damaged by polio and had sprouted have been overworked for 40 years and can no longer take the strain. So too, overworked muscles ache and joints hurt after decades of doing too much work with too little muscle support.

## Is PPS A Progressive Disease?

No. PPS is neither progressive nor a disease. PPS are just the body growing tired of doing too much work with too few damaged and overworked neurons.

## Is There Any Treatment For PPS?

Yes! Since PPS symptoms are caused by the nervous system equivalent of plugging too many appliances into one electrical outlet, polio survivors simply have to unplug some of the appliances. Polio survivors must decrease the overuse to stop the abuse of their damaged nerves, weakened muscles and painful joints.

## What Are The Treatments For PPS?

Polio survivors basically need to conserve energy to stop blowing their bodies uses. Polio survivors must walk less, use needed assistive devices (a brace, crutches, a scooter), stop working before symptoms come on, and plan rest periods throughout the day.

## Are Treatments For PPS Effective?

Yes. The worst-case is that patients who stop the overuse abuse will have their PPS symptoms plateau. However, when survivors start taking care of themselves, the overwhelming majority have noticeable decreases in fatigue, weakness and pain. Isn't exercise the only way to strengthen weakened muscles?

*No.* Since PPS symptoms result from too many appliances being plugged into a overloaded nervous system, muscle strengthening exercise would be like plugging in a dozen additional toasters. While stretching exercise can be helpful, pumping iron and feeling the burn means that polio-damaged neurons are burning out. Also, polio survivors typically cant exercise they way others do to condition their hearts and try to prevent osteoporosis.

## What Can Friends And Family Do To Help?

Polio survivors have spent their lives trying to look and act normal. Using a brace they discarded 30 years ago and reducing their typically super-active daily schedule is both frightening and difficult to do. So, friends and family need to be supportive of life-style changes, accept survivors physical limitations and their new devices. Most importantly, friends and family need to be willing, when asked, to do the physical tasks polio survivors probably could do, but should not do any longer.

Friends and family need to know everything about PPS and say nothing. Neither gentle reminders nor wellmeaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of their own bodies and ask for help when it's needed.

### Happy Birthday



February Edie Porter - 4 Sharon Underwood –4 Sandra Bath –16 Charles Johnson –22

#### March

Barry Turner - 2 Thelma Tillotson --4 Lavonne Calandra --7 Della Simmons --14 Glenda Walker --14 Terri Dunnermann --18 Robert Stinnett --18 BJ Vance --22 Roy Tillotson - 24

#### With Love, from Your CEPSA Family

#### Dear Janet,



Just to let you know That we're continuing to pray That you will soon recover And get stronger every day We're praying that you'd have God's peace in your soul And feel His arms around you As He heals and makes you whole. © By M.S. Lowndes

#### Please send your well wishes to Janet at:

Janet DiClaudio Room B25 Eagle Health and Rehabilitation 405 S. College St. Statesboro, GA 30458 (912)764-6108

### Quote of the Month



"We are each of us angels with only one wing, and we can only fly by embracing one another." -Lucrecius

#### **Member Concerns**

Wakil Carter, Janet DiClaudio, Richard Graham, Nancy Hess, Charlotte Richter, Penny Smith, Gigi Veccia & Jim Veccia

#### Please keep these members in your prayers.

### FOR YOUR INFORMATION

#### Georgia Center for Nonprofits

The Coastal Empire Polio Survivors Association was welcomed by the Georgia Center for Nonprofits. CEPSA was listed as one of the "New Organizational Members" in the "Community" section of the Spring, 2012 issue of "GEORGIA NONPROFIT NOW."

#### Social Security News: PAPER CHECKS WILL END

On March 1,2013 the United States Treasury will stop mailing paper checks to Social Security beneficiaries. If you do not choose to receive your benefits via direct deposit to a bank or credit union account or have it loaded onto a Direct Express Debit MasterCard by March 1, you will receive your benefits loaded onto a pre-paid debit card.

**Did you know?** Social Security payments increased in 2013 by 1.7%. This latest increase is much less than the 3.6% cost of living adjustment for 2012.

#### Prescription Drug Drop-off Box

A prescription drug drop-off box is now available to anyone needing to dispose of prescription drugs. It is located at the Armstrong Atlantic Police Department, 11935 Abercorn Street, in Savannah, Georgia.

Armstrong Atlantic was selected to be the drop-off location by the Medical Association of Georgia. It was made possible through their program, the Think About It campaign.

The box offers a place to dispose of unused prescription drugs that might otherwise be disposed of improperly. Anyone can drop-off prescription drugs, year-round, on any day, and it is entirely confidential.

You may contact the Armstrong Atlantic Police Department at 912-344-3333 if you need further information.

From an article submitted by CEPSA member Cheryl Brackin. Savannah Morning News [Savannah] 24 January 2013: 7A

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Contact Mark Swift at 920-2414 or <u>mswift@lifecil.com</u> for additional info.

# SHAKING SALT, SUGAR FROM YOUR DIET . . .

#### **Consumer Reports Magazine**

It's no accident that salt and sugar permeate the nation's food supply. Both are inexpensive palate pleasers and food manufacturers use them liberally to satisfy people's penchant for things salty and sweet. According to a recent issue of *Consumer Reports On Health*, the average American today consumes nearly twice the recommended maximum of sodium and nearly 460 nutritionally empty calories of added sugar every day.

Over indulging these particular taste buds can have serious health consequences. A high sodium diet not only increases the risk of high blood pressure and subsequent heart attack, kidney disease and stroke but possibly causes osteoporosis and kidney stones (by increasing the secretion of calcium into the urine), stomach cancer (by damaging the protective mucus membrane) and asthma (by making lungs more susceptible to irritants).

And all those sugar calories probably contribute to Americans' expanding waistlines. Unfortunately, consuming less sugar and salt isn't easy. Three quarters of the sodium in Americans' diet comes from processed packaged and prepared foods; even products that don't taste salty, such as breads and other baked goods, often contain large amounts. And many apparently nutritious foods pack far more of the sweet stuff than people might expect. Still, the editors of *Consumer Reports On Health* say that cutting back on both is possible. Leaving salt behind. It is recommended that most adults



get no more than 2,300 milligrams of sodium a day —the amount, roughly, in one teaspoon of table salt. People with a systolic blood pressure over 120 millimeters of mercury (mm/Hg) or a diastolic pressure over 80mm/Hg should aim for 1,500 milligrams. The editors of CROH recommend the to reduce sodium intake:

following tips to reduce sodium intake:

**Retrain your taste buds.** Scale back the amount of salt used at the table and in cooking to reduce your exposure to the taste. After three months, most people no longer miss salt, research shows.

**Check nutrient claims.** Products labeled 'sodium-free' contain 5 mg of sodium or less per serving. A 'very low' sodium item contains 140mg or less.

**Rinse your food.** Running water over canned tuna and salmon, canned vegetables, feta cheese and capers can reduce the sodium load by up to 30 percent.

**Swap spices for salt.** Cook with fresh or dried herbs, saltfree seasoning blends and acidic flavorings like lemon juice and flavored vinegars to bring out a food's natural taste.

**Sugar blues.** Some of the supposed dietary dangers of sugar, such as that it causes hyperactivity have been debunked.

And indulging a sweet tooth won't lead to diabetes; even people who have it can safely eat a sugary snack if it's factored into their meal plan. However, sugar is guilty as charged for nourishing the bacteria that



cause dental cavities. And while there's nothing inherently fattening about sugar, it's probably not coincidental that the nation's ongoing obesity epidemic has progressed in step with its sugar consumption: Americans today consume 15 percent more added sugars than they did 25 years or so ago.

## **MORE TIPS**

Consumer Reports on Health offers the following tips for people to subtract added sugars from their diets.

Choose sweets that contain some needed nutrients. To satisfy a craving for sweets, opt for fruit, low-fat chocolate milk, lightly sweetened whole-grain cereal, or plain yogurt flavored with fresh fruits.

Swap candy for healthy snacks. Opt for dry-roasted nuts, air-popped popcorn or baked tortilla chips.

Cook creatively. Experiment with cardamom, cinnamon, coriander, ginger and nutmeg, which add sweetness and flavor. Try substituting 100 percent fruit juice for honey or other liquid sweeteners.

Source: The Daytona Beach News-Journal, FL, January 28, 2008.

Reprinted from Second Time Around, January 2010—Publication Of Boca Area Post Polio Group, Boca Raton, Fl.

# Inflammation And Pain

Research by Diane Davis

Research shows that some foods pack as much painfighting power as common pain medications. Try adding at least one serving of each of the following foods to your diet on a daily basis to help fight inflammation and pain. Eat as much unprocessed organically grown food as possible for optimal health.

**1. Red Grapes** — Red grapes contain resveratrol, a powerful compound that blocks the enzymes that contribute to tissue degeneration. Research suggests that resveratrol protects against the kind of cartilage damage that causes back pain.

**2. Cherries** - Eating cherries daily can significantly reduce inflammation. Cherries are packed with antioxidants and are relatively low on the glycemic index. A handful of dark red cherries before bedtime will also help you sleep.



• **Tip:** Melatonin-rich concentrated tart cherry juice is shown to reduce inflammation and help you get a better night's sleep. Drink 1 ounce of concentrated tart cherry juice twice a day. Try R.W. Knudsen "Just Tart Cherry Juice." 100% juice, no sugar added, no preservatives or artificial flavors. <u>Kroger in</u> <u>the organic section</u>.

- **Tip:** Frozen cherries are available all year long and make a tasty dessert with a little yogurt or cheese.
- **Tip:** Dark red and purple fruit juices like grape, pomegranate, acai, blueberry and cranberry are best. Choose 100% juice, no sugar added, no preservatives or artificial flavors. When possible, choose juice that is not from concentrate which has more calories. Bolthouse Farms is a good brand.

**3. Blueberries** —Blueberries are full of natural compounds that reduce inflammation and protect the <u>brain</u> from many of the effects of aging and mental decline. As we get older, damaged cells accumulate in the brain, which can lead to <u>age-related diseases</u> such as <u>dementia</u>, <u>Alzheimer's</u>, and <u>Parkinson's</u>. Polyphenols in berries activate proteins that "clean up" damaged cells, breaking down and recycling the toxic chemicals linked to age-related mental decline. <u>Blueberries</u> rank first among fruits for their antioxidant powers, strawberries are tops in vitamin C, and acai berries contain high levels of omega-6 and -9 fatty acids, which play a role in cardiovascular health.



• **Tip:** Add berries to cereal, purée them in sauces and smoothies or just eat them fresh with yogurt.

• **Tip:** Frozen berries are usually less expensive than fresh -- and just as good for you. Let thaw and top your cereal each morning.

**4. Fresh Pineapple** - Pineapple is a member of the bromeliad family, which is considered an effective antiinflammatory. Regular ingestion of at least one cup of fresh pineapple daily will help relieve painful joints common to osteoarthritis and reduce inflammation and swelling. Pineapple is high in manganese, a mineral that is critical to development of strong bones and connective tissue. It is helpful to older adults, whose bones tend to become brittle with age. Pineapple aids indigestion and helps the body digest proteins more efficiently. Those individuals who eat fresh pineapple daily report fewer sinus problems related to allergies.



• **Shopping Tip:** Pineapples stop ripening the minute they are picked. There is no special way of storing them that will help ripen pineapple further. Choose your pineapple by smell. If it smells fresh, tropical and sweet, it will be a good fruit. The more scales on the pineapple the sweeter and juicier the taste.

5. Cruciferous Vegetables - Broccoli, cauliflower, brussels sprouts, and kale are loaded with antioxidants. However, they provide one other ingredient "sulfur," which the body needs to make its own high-powered antioxidants.

**6.** Salads - Dark-green lettuce, spinach, tomatoes, and other salad veggies are rich in vitamin C and other antioxidant nutrients that reduce inflammation.



• **Tip:** Choose olive-oil-and-vinegar salad dressing (vinegar helps moderate blood sugar) and skip croutons.

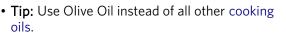
**7. Green Tea -** Like fruits and vegetables, green tea contains natural anti-inflammatory compounds. It may even reduce the risk of heart disease and cancer.

- **Tip:** Drink at least a cup a day -- brew it like sun tea, refrigerate, and serve.
- **Tip:** Best if you sweeten a cup of hot green tea with 100% pomegranate juice rather than sugar.

**8.** Olive Oil - Olive oil is a great source of oleic acid, another anti-inflammatory. Research shows that those who consume more oleic acid have better insulin function and lower blood sugar.



• **Shopping Tip:** Choose extra-virgin olive oil, which is the least processed.



**9. Turmeric** - One of the main healthful ingredients in turmeric is curcumin (a curcuminoid). Turmeric is an antioxidant that helps prevent cell damage, promotes your immune system, fights cancer, strengthens bones, serves as a natural anti-inflammatory, keeps the skin supple, and calms the digestive system. Turmeric is found in curry powder as the main ingredient, but this is not a good source of turmeric because curry powder has many other ingredients, which may be harmful to the body if used very often. Therefore, turmeric should be purchased alone. As with all supplements, talk with your doctor or pharmacist before taking turmeric.

You can find turmeric at health stores in powder form or capsule form.



• **Tip:** <u>Turmeric Powder</u> - Just a teaspoon or two in your foods will help you get all the benefits of this great herb. Best if not cooked in foods.

• **Tip:** <u>Turmeric Capsule</u> —Look for high quality, 100% organic-based turmeric supplement.

**10. Ginger** - Ginger is rich in inflammation-fighting compounds, such as gingerols, which help to reduce the aches of osteoarthritis and soothe sore muscles.



• **Tip:** Brew your own ginger tea. Use a peeler to remove the skin off a piece of ginger root, then add several thin slices to a cup of hot water and let steep for a few minutes or add it to a cup of green tea.

**11.Salmon** - Salmon is a cold-water fatty fish that is rich in omega-3 fatty acids, which can lower blood fats called triglycerides to help prevent heart disease, protect brain cells, suppress inflammation and help arthritis pain. In a new study, eating fatty fish just once a week cuts the risk of Alzheimer's disease by 60%. Other cold-water fish that contain omega-3 are sardines (fresh and canned), mackerel, herring and tuna. Try to eat cold-water fatty fish 2 or 3 times a week.



- **Tip:** With increasing public concerns over farmed salmon, <u>choose wild salmon</u>. Check labels, most canned salmon are wild.
- Tip: <u>All salmon from Alaska is wild, and</u> <u>Atlantic salmon is usually farmed</u>.

# **Elevated Toilet Seat**

In the January, 2013 issue of THE LIGHTHOUSE, we featured a "toilet elevator" that can be installed between the floor and the toilet bowl. This type of installation eliminates the need for bulky additions to the seat and looks great. As was mentioned in the article, installing the "toilet elevator" requires a plumber, doesn't look like an addition and is a more permanent option.

We came across the "Home Care" by Moen, "White Elevated Toilet Seat. "This type of seat is ideal for those people that don't want to or can't hire a plumber or for those that may live in a rental. The seat addition can be removed and taken with you if you move. It has "handles" built in that give you support when attempting to stand from a sitting position.

The seat: exceeds ADA requirements with a 300 lb. capacity, has a contoured, wider seat, has support handles and comes with a locking bracket that allows it to be securely attached to the toilet.

The seat shown below is available at Lowe's, store #0403, located at 11114 Abercorn Street, Savannah, GA 31419. Check with your local Lowe's for availability.



Home Care by Moen, White Elevated Toilet Seat Lowe's Item #: 39632 Model #: DN8070 \$55.98





Photos Courtesy of Linda Clas Rosario

Article submitted by CEPSA member Diane Davis.

# **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:

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Thank you for your support and encouragement.



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Shining Light on Post-Polio Health

CEPSA's next meeting is on Saturday, February 23, 2013, 10:30 AM at The Exchange on Waters 6710 Waters Avenue Savannah, GA 31406