



# THE LIGHTHOUSE

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

April, 2014 Newsletter

[www.coastalempirepoliosurvivors.org](http://www.coastalempirepoliosurvivors.org)

Vol. XVII, No. 4

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## *The President's Message...*



**C**EPSA Members and Friends, we have reached another proud milestone. Our organization is celebrating its 17<sup>th</sup> anniversary at our April 26 meeting. In the early years none of us ever dreamed that we would reach so many polio survivors and achieve so much. 2013 was a busy year, and 2014 is proving to be an active one as well.

Hats off to our executive board members with their many talents. We are fortunate to have such a strong, committed group guiding the organization. Most have served for many years. Likewise, I commend the active members who attend meetings and support each other. We appreciate our inactive members who cannot be with us. Your care team leaders enjoy talking to you and maintaining your link to CEPSA.

Mark your calendars for April 26. Join us at the Marsh Auditorium in Candler Hospital when three survivors will tell their polio stories. Following their talks we will have lunch provided by CEPSA. This will give us time to visit with each other. I always look forward to this informal time when we can catch up with members we do not see often. Meeting at the Marsh for our anniversary is a tradition, because it provides adequate space. Note that we **will not meet** in the Lewis building, our new meeting location, for this special event. When your care team leader calls you this month, please respond. We need an accurate count of those planning to attend, so that enough food can be ordered.

We had a very informative and pertinent meeting on March 22. Many thanks to Attorney Robert W. Bush of Georgia Legal Services who reminded us of the important legal paperwork each of us needs to have in place. He stressed the importance of having the durable power of attorney for healthcare, above all other documents. We sincerely appreciate Robert's willingness to share his time and knowledge with us. If you do not have computer access to acquire a blank Georgia or South Carolina durable power of attorney for healthcare form, please let me know. A form can be printed and mailed to you. Contact me at 912-927-8332.

Plan now to attend our 17<sup>th</sup> anniversary celebration April 26. Join your CEPSA friends on this special day when we will be revisiting the past and moving forward into the future.

Cheryl Brackin, President

## **Next Meeting**

Saturday,

**April 26, 2014**

10:30 AM

**in the Candler Hospital**

**Main Building,**

**first floor,**

**Marsh Auditorium**

**5353 Reynolds Street, Savannah, GA 31405**

Coastal Empire Polio Survivors Association, Inc.

## General Meeting Minutes

March 22, 2014

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

**Call to Order/Welcome:** President Cheryl Brackin called the meeting to order at 10:36am and thanked those in attendance.

**Pledge of Allegiance:** Lorraine Frew led the Pledge of Allegiance.

**Inspiration:** Terri Dunnermann gave the inspiration, reading the story "The Motivated Little Frog." The moral of the story was "Don't listen to the naysayers; we can overcome many challenges."

**Program:** Cheryl then introduced our guest speaker Robert W. Bush, Senior Staff Attorney, Georgia Legal Services. His topic was "Managing Expectations: Important Legal Documents." His office is well versed on assisting those in need of legal assistance, including issues of those persons over the age of 60. They can assist in nursing home issues, elder abuse, home care, and various other issues based on each case. This is a non-profit organization, and charges are based on the client's financial resources. Robert explained the most important legal documents are a durable power of attorney for health care, conditional financial power of attorney, and a will. The most important take-away from this presentation was the critical importance of choosing an advocate who will act as our agent to make sure our health and financial expectations are carried out when we are unable to speak for ourselves. The Georgia Legal Services office is located at 6602 Abercorn Street, Suite 203.

### Business Meeting:

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

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

**Care Team Reports:** The care team leaders reported concerns about Hattie Evensen, Robert Allen, Jim Veccia, Barry Turner, Diane Davis, Charlotte Richter and Janet DiClaudio. Many members did not return calls, and we hope for the best.

**Old Business:** April Anniversary Meeting: Care team leaders have been asked to contact our members and identify those attending the April 26th Anniversary Celebration of 17 Years of CEP SA. We need the count by April 19<sup>th</sup>, so that Adrienne can order the correct amount

of food. The event will be at the Marsh Auditorium at Candler Hospital. Cheryl announced that three members will tell their polio stories.

**New Business:** There was no new business addressed.

The meeting was adjourned at 12:02 pm.

Respectfully submitted,  
Michael Dunnermann, Secretary

**Attendance:** Cheryl Brackin, Wanda & Carlos Clas, Michael & Terri Dunnermann, Lavonne Calandra, Sissy Morel, Betty Goff, Lorraine Frew, Joan & Alan Page, Nancy & Steve Hess, Della and Esther Simmons.

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

CEPSA  
P.O. Box 14252  
Savannah, GA 31416

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

*Thank you.*

## 2014 MEETING SCHEDULE

Wanda and Carlos Clas made a bookmark/2014 meeting calendar as an attachment to our December banquet program. If you did not detach it or did not attend the banquet, below is a list of our remaining meeting dates for the year. Remember that we always meet on Saturdays at the Lewis Building on Reynolds Avenue, unless otherwise indicated.



### Upcoming Meeting Dates

**April 26, 2014 @ Marsh Auditorium--Candler**

May 17, 2014 @ \*\*\*

June 28, 2014 @ \*\*\*

July & August - No Meetings

August 2, 2014 - Summer Luncheon

noontime, Dutch treat

September 27, 2014 @ \*\*\*

October 25, 2014 @ \*\*\*

November - No Meeting

December 6, 2014 @ Hilton Garden Inn

**\*\*\* (General Meetings)**

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

## Our April Program

Our April 26 meeting is our anniversary celebration of 17 years as a support group. The two surviving founders and numerous charter members did not dream that CEP SA still would be the viable, productive organization it is today. We will meet in the Marsh Auditorium of Candler Hospital. You can reach the auditorium through the front entrance of the hospital. We plan to have some volunteer spouses in the lobby to push anyone needing to use one of the wheelchairs, available in the lobby. An easier way is parking near the left end of the hospital and going in through the garden area. Once again we will be asking the Security Department of Candler Hospital to provide golf cart rides to members from the parking lot through the garden to the door near the Marsh. If you have any concerns or questions about accessing the meeting location, please call Cheryl at 912-927-8332 prior to the meeting date.

## Scooter Search

We need to locate a large scooter with three wheels, not a power chair, for one of our members. Please keep your eyes and ears on alert for the availability and possible donation of such a scooter. Contact Richard Graham if you learn about any possibilities.



## FREE EYE EXAM !

and if you qualify...

## FREE EYEGLASSES !

**When:** Thursday, May 1, 2014  
at 9:00am - 12:30pm

**Where:** The Social Apostolate,  
502 East Liberty Street  
(at Price Street)

**What to Bring:** A current,  
valid ID and yourself !

Priority will be given to diabetics (bring proof)  
and the elderly. After that, it's  
"first come, first served."

## You're Invited to CEPSA's 17th Anniversary Celebration.



When : Saturday, April 26, 2014

Where : Candler Hospital's Marsh Auditorium  
5353 Reynolds St., Savannah, GA 31405

Time : 10:30 AM

*Our program* will consist of  
three of our members,  
Joan Page, Susan Pineo and Tom Schendorf,  
telling their "Polio Stories."

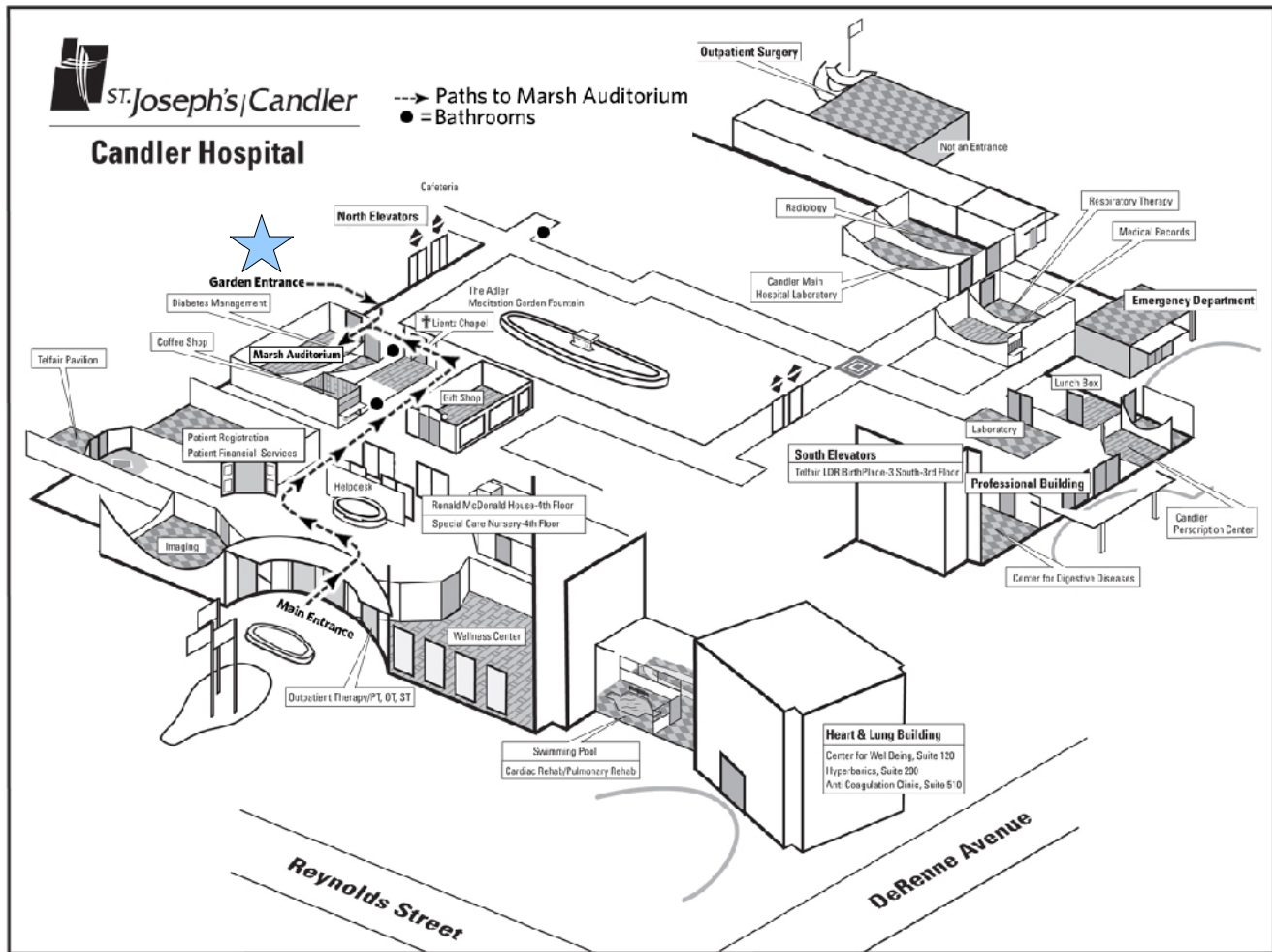
Then you will be treated to a delicious lunch.  
The luncheon plans are being arranged by  
Adrienne, Terri, Betty and Lavonne.  
These ladies have done an outstanding job  
every year. We thank them for all their hard  
work.

**For your comfort**, we suggest you bring a sweater  
or jacket and a pillow or cushion to sit on.

*Please let your Care Team leaders know  
if you will be attending and  
if you will be bringing any guests.*

*See next page for floor and parking maps  
of Candler Hospital.*

## Candler Hospital Main Floor Map & Parking Map

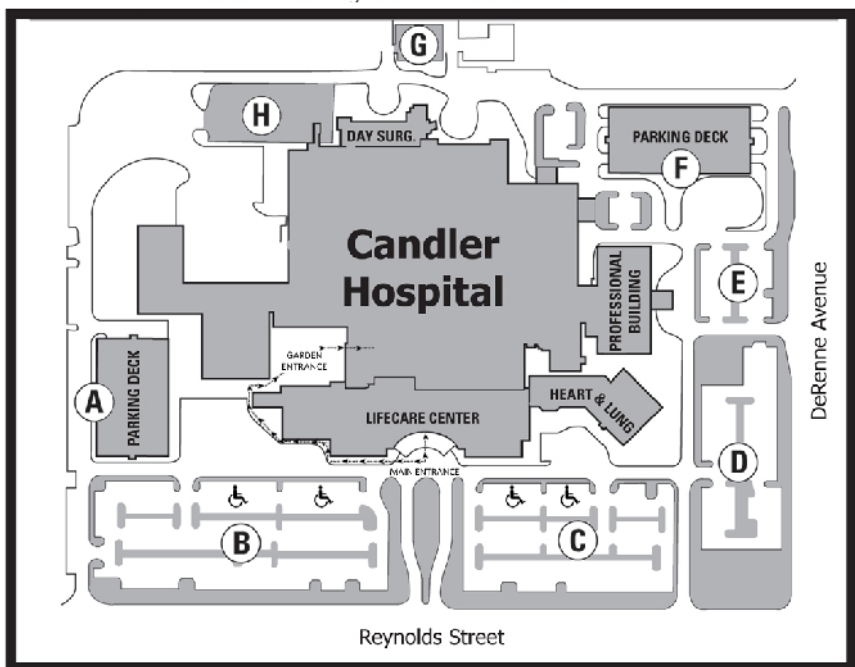


AD20124 (7/10)

★ Edward Proctor, director of the security department at Candler Hospital, said CEPSA members can enter the hallway near the Marsh Auditorium through the accessible (automatic) door off the garden. This will allow us to park at the far left end of the parking lot when facing the front of the building. There will be security officers on duty April 26. They will use a golf cart to transport members from their cars to the automatic door. Call them at 663-3897 or 819-6333 for this assistance.

Please be aware that the officers might not be available if there is any type of emergency on the hospital campus.

Candler: Parking Areas A thru H and Aerial View



Maps courtesy <http://www.sjchs.org/images/CH%20interior%20map%201200.jpg> and <http://www.sjchs.org/images/CH%20parking%20map%201200.jpg>



# What Your Voice is Saying About You: Vocal Changes and the Late Effects of Polio

Mary Spremulli, MA, CCC-SLP, Punta Gorda, Florida, [info@voiceaerobicsdvd.com](mailto:info@voiceaerobicsdvd.com)

*A speech-language pathologist in private practice, a clinical consultant with Passy-Muir, Inc. and a national seminar leader on medical topics, Mary Spremulli addresses how voice changes may relate to polio survivors, a topic raised frequently by PHI readers.*

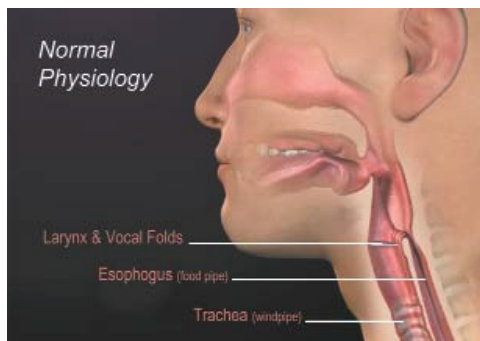


Image courtesy of Passy-Muir, Inc., Irvine, CA.

## What is your voice saying about you?

*"Our voice resonates with life. Because this is so, it can touch the lives of others. The caring and compassion imbued in your voice finds passage to the listener's soul, striking his or her heart and causing it to sing out; the human voice summons something profound from deep within, and can even compel a person into action." – Daisaku Ikeda, Buddhist Philosopher*

## Why does my voice sound this way?

Over the last few years, a number of individuals with a history of polio 40 or 50 years ago have been referred to my speech pathology practice complaining of changes in their vocal function. They were often young children at the onset of their polio, so some of them are unsure if their original diagnosis was bulbar or spinal.

Now, many of them in their 60s or 70s report voice problems or changes, such as: "my voice is weaker," "my voice gives out by the end of the day," "my voice is scratchy and hoarse." Not infrequently, these changes in voice are accompanied by changes in swallowing function with associated complaints of increased "choking" when eating or drinking.

## Is this related to having had polio?

In many of these instances, the change in voice can represent further weakening of the respiratory and phonatory (voice production) system. In particular, if individuals had initial bulbar polio symptoms, they have likely already spent a lifetime using some compensatory respiratory and oral-pharyngeal muscle function. This muscle function may now be further weakened due to further muscle degeneration, age-related changes, muscle

disuse atrophy or vocal misuse. Separating out the causes and contributors to current voice problems can be challenging for the voice therapist or otolaryngologist.

## Why should I see an Ear, Nose, and Throat Doctor (ENT)?

Any sudden change in voice function, or any change, such as hoarseness, that persists for more than a few weeks warrants an examination by an ENT. The ENT will conduct a direct visualization of your vocal folds and larynx (voice box) by passing a small scope with a camera through your nose and making sure there are no growths, such as nodules (calluses that form from misuse) or polyps (a usually benign, fluid-filled outgrowth of tissue that also may be from misuse) or tissue changes suggesting a more serious diagnosis.

A direct visualization can also confirm the contribution of acid reflux, in particular stomach acid that escapes from the top muscle of the esophagus (food pipe). This type of reflux, is also referred to as laryngopharyngeal reflux or "silent reflux," and it is often a factor causing hoarseness or other voice changes.

Patients are often surprised when the ENT prescribes anti-acid medication for their voice changes, not realizing that our anatomic design places the opening of the esophagus and the opening to the windpipe dangerously close, and the vocal folds often receive the insult of acid which may escape from the top muscle of the esophagus.

## What is a voice evaluation?

Following an ENT examination, patients are typically referred to a speechlanguage pathologist (voice therapist), who may conduct further instrumental examination using videostroboscopy. In videostroboscopy, a rigid scope with a camera attachment is placed through the mouth to visualize the larynx and evaluate the dynamic movement of the vocal folds.

The voice therapist will also perform a clinical evaluation of vocal function. This exam involves taking a thorough history that includes questions about how you use your voice throughout the day, medication use that may be affecting your voice – particularly inhalers and steroids – as well as any surgery you may have had on your throat or any tubes placed down your throat during surgery or in an emergency to maintain ventilation. Measurements of pitch, vocal intensity and voice duration are obtained, as well as observations of your respiratory patterns.

In addition to this history and perceptual data, the voice therapist will observe how you use your breath support and voice during conversational speech. Behaviors that can harm the vocal folds, such as frequent throat clearing or coughing, will also be noted as these common habits over time can injure the vocal folds. You will likely also be asked about hearing, since a decline in hearing may cause difficulty in your ability to accurately judge vocal intensity in your own voice or others.

Although not directly related to voice production, the vocal

folds' position at the opening of the windpipe also makes them gatekeepers against foreign bodies entering into the upper airway. Therefore, you will be asked about any problems you may be having with choking or coughing when eating or drinking. These symptoms may also be an indication that the sensation of the larynx or function of the vocal folds have declined in some way, permitting food or liquid to now enter your upper airway. A separate swallowing evaluation may be recommended.

### Can voice therapy help?

Once an accurate diagnosis of your voice problem is made, treatment will likely be a combination of medical and therapeutic management. Problems requiring further medical treatment will be handled by the ENT. These may include medications to treat acid reflux, thin/thick mucus/secretions or to reduce post-nasal drainage. More serious problems, such as polyps, may require surgery.

The voice therapist will focus on vocal hygiene, which includes modification of environmental factors that may be serving as irritants to the larynx and vocal folds, instruction in methods to eliminate throat clearing and other abusive habits, and encouraging improved hydration through water intake and/or steam.

Then, much like a music teacher, the remainder of voice treatment will focus on improving functional use of your voice instrument. In the case of someone with poor diaphragmatic breathing and respiratory muscle use due to polio and post-polio symptoms, a modified respiratory muscle training program may be recommended.

Relaxation techniques and methods to reduce muscle straining in the neck muscles and larynx may be demonstrated. Use of optimal pitch and posture and techniques for improving loudness without straining will all be emphasized. Voice treatment may be offered for six to eight visits, with development of a home exercise program to encourage strengthening of the system, preservation of muscle function and maintenance of any improvement achieved. For individuals with voice changes from PPS, conservation techniques, including use of personal voice amplification devices may also be beneficial.

Our larynx is a rather amazing organ. Our ability to use its shared functions of breathing, digestion and voice production make it clearly one of our uniquely human gifts. Throughout our lives, our voice mirrors physical growth and other body changes. It conveys our physical and emotional health, and at times, it inspires poetry.

Mary Spremulli, MA, CCC-SLP, is the author of *Voice Aerobics DVD*, a three-part voice and exercise workout, *Voice Aerobics Grand Slam™* and *Voice Aerobics CD Songbirds™*, speech and vocal exercise set to music ([www.VoiceAerobicsDVD.com](http://www.VoiceAerobicsDVD.com)). A speech-language pathologist in private practice, she leads national seminars on medical topics and serves as a clinical consultant with Passy-Muir, Inc. ([www.passymuir.com](http://www.passymuir.com)), manufacturer of tracheostomy and ventilator swallowing and speaking valves.

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## Famous Polio Survivors- Part 2

Did you ever have a Steiff teddy bear with a button in its left ear? Margarete Steiff, founder of the Steiff Company in 1880, had polio as a child, never walked again, and used a cane-backed wheelchair. Steiff hired as many disabled people as possible to work in her factory. Her motto was "Only the best is good enough for children."

Ed Roberts, who had polio at age 14 years in 1953, is considered the father of the independent living movement. He spent 18 months in hospitals and returned home paralyzed from the neck down except for two fingers on one hand and several toes. With some resistance from the administration Roberts was admitted to the University of California at Berkeley, where one dean said "We've tried cripples here before and it didn't work." He was housed in an empty room which accommodated his iron lung in a wing of Cowell Hospital, a campus medical facility. More severely disabled students were admitted and lived in Cowell. They formed the group called the "Rolling Quads," who created a positive expression of disability identity. Roberts obtained bachelor's and master's degrees in political science. He was an early director of the Berkeley Center for Independent Living, the first independent living service and advocacy program run by and for individuals with disabilities.

Itzak Perlman, violinist extraordinaire, contracted polio in 1949 at age four years. Perlman wanted to begin violin lessons at age three years, but was told he was too small to hold a violin. He began teaching himself on a toy violin. After recovering from polio, he was enrolled at the Music Academy of Tel Aviv. Perlman has become one of the greatest violinists in the world and performs in a seated position. He has earned several Grammy and Emmy awards and was given the Kennedy Center Honors in 2003. He walks with bilateral braces and crutches and also uses a scooter. Your editor had the honor of attending a performance by Perlman here in Savannah in the 1980s.

Any jazz fans out there? David Sanborn, famous alto saxophonist, contracted polio at age three years in St. Louis, Missouri. Initially he was in an iron lung for a year, followed by two years in bed. Sanborn listened to music while he recovered. He was advised by a physician to play a wind instrument to strengthen his weakened chest muscles and improve his breathing. He has earned six Grammy awards and has had six gold albums and one platinum. Sanborn is experiencing post-polio syndrome, but continues to tour and perform.

Katherine Jackson, the famous matriarch of the musical Jackson family, had polio as an infant in Alabama. She had multiple surgeries, used braces and crutches until she was 16 years of age, and walks with a limp. Jackson worked at Sears for a time and then stayed home to raise her large family. As her older sons began performing, she noticed the talents of her four-year-old son Michael before his father did. In 1985 *Essence* magazine honored Jackson as "Mother

of the Year" for her positive impact on the musical careers of her children.

Dr. Lauro Halstead, polio survivor and polio physician, contracted the disease at 18 years of age while traveling in Spain. His paralyzed right arm never recovered. Halstead devised ways of managing during his medical training. He said "...one of the messages I learned with my polio, is that you learn to compensate in ways that the average person can't even conceive of." For example, he developed a method for drawing blood using one hand. Dr. Halstead's 50-year career was focused on treating patients with spinal cord injuries and post-polio syndrome. Several CEPSA members have read his books on PPS, including *Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome* (2006). He retired from the National Rehabilitation Hospital in Washington, D.C. in 2012. Your editor had the privilege of hearing Dr. Halstead speak at a Polio Health International Conference in the late 1990's in St. Louis.

## DD Day Coming- That's Data Destruction Day!

Data Destruction Day is scheduled for Saturday, May 5, 9:00am-2:00pm at the Chatham County Resource Conservation Education Center at 1321 Eisenhower Drive. The facility is located across the street from SouthCoast Medical. You simply drive through to have your unwanted but important data taken from your vehicle and shredded on site. For those of us with post-polio syndrome and arthritis this is a wonderful service. There is no charge. The event is being sponsored by the Chatham County Resource Conservation Education Center, WSAV TV, Keep Chatham Beautiful, and Cintas. Goodwill will be accepting old electronics at the event.

Did you know that you can drop recyclables at the Resource Center Tuesday-Saturday, 8:30am-5:00pm? They accept the usual items, such as newspapers, magazines, cardboard, glass, plastics #1 and 2, cans, office paper, and plastic shopping bags. You also can drop off used cooking oil, used motor oil, used eye glasses, used ink and toner cartridges, old CDs, mobile phones, scrap metal, and black plastic plant nursery pots. Shoebox Recycling just began there. Men's, women's, and children's shoes in good usable condition in pairs can be dropped off. Their website says "Our shoes are for reuse all around the globe, putting landfills on diets and teaching all that worn does not mean worn out."

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 CEPSA, CEPSA'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. CEPSA, CEPSA's THE LIGHTHOUSE and its editors do not assume any responsibility for an individual's actions.



### April

Fred Davis - 2  
Jim Lampke - 3  
Sissy Morel - 6  
Tom Newcomer - 6  
Marty Foxx - 8

### May

Bob Parkhurst - 6  
Esther G. Simmons - 13  
Allen Igou - 17  
Becky Cheatham - 19  
Wanda Clas - 19  
Jan Schendorf - 19  
Dale Merritt - 26  
Richard Graham - 31

## Member Concerns

Robert Allen, Diane Davis, Janet DiClaudio,  
Terri Dunnermann, Hattie Evensen,  
Bobby Johnson, Patrina Johnson, Ed Luck,  
Marie McManus & Charlotte Richter.

*Please keep these members in your prayers.*

## Congratulations to the Lucks!

CEPSA sends warm congratulations to Sally and Ed Luck on the birth of their third great grandson Andrew Stephen Jones on April 2. Drew weighed 6 pounds, 3 ounces and is doing well, even though he arrived 2 weeks early. The proud grandparents stayed up all night waiting with the rest of the family. The Joneses will return to Southeast Asia in June, and Sally and Ed will watch Baby Drew grow on Skype.

## Great Thanks!!

As editor of The Lighthouse I want to thank our "underground" co-editor. Wanda Clas has helped me on all the newsletter issues in 2014. Carlos photo-shopped and arranged our December banquet pictures in the January issue. Wanda recently typed new mailing labels with our new p.o. box number on them.

Michael Dunnermann made trips to the Lewis building where we are meeting in order to learn about the AV equipment in the room. Our engineer/CEPSA secretary now can show our DVDs of previous programs and also some that we purchased. So if you missed lectures by some of our best presenters, you still can hear them.

It is people like the Clases and Michael behind the scenes that keep CEPSE going. There are numerous others not acknowledged here. We'd never have come this far without so many willing members donating their time and talents.



Coastal Empire Polio Survivors Assoc., Inc.  
P.O. Box 14252, Savannah, GA 31416  
GA (912) 355-1221 • SC (843) 837-1230  
E-mail: CEP5A05@msn.com  
www.coastalempirepoliosurvivors.org

*Shining Light on Post-Polio Health*

**Next Meeting**  
Saturday,  
**April 26, 2014**  
10:30 AM  
in the Candler Hospital  
Main Building, first floor,  
Marsh Auditorium.  
5353 Reynolds Street  
Savannah, GA 31405



## **CONTRIBUTIONS**

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

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

Your contributions are tax deductible and will be acknowledged appropriately.

Please complete this form and mail it along with your check to: **CEPSA**

**P.O. Box 14252, Savannah, GA 31416.**

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.***