



# THE LIGHTHOUSE

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

April, 2013 Newsletter

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

Vol. XVI, No. 4

# SWEET SWEET 16

## The President's Message...

**T**he dream lives on! Shirley Carnell, RN and CEPSPA founder/mentor, cared about you, even though she did not know you. She wanted polio survivors to have a place to gather, to support each other, and to learn about post-polio syndrome. Her inappropriate, devastating

treatment led to her selfless determination to start a support group. Shirley dreamed that we could learn by sharing our polio journeys and PPS problems, and so we have. She dreamed that we could educate medical professionals about PPS, and so we have. She dreamed that we could raise funds to help survivors with medical treatment and equipment, and so we have.

Shirley approached Lorraine Frew and me, asking us to join in her efforts. We could not refuse, and CEPSPA was begun in 1997. Recently I reread the April 2010 president's message by Jim Veccia. He wondered whether the founders ever dreamed that CEPSPA would be the organization that it is today. Certainly we had hopes and dreams, but those have been far surpassed. I believe our success has been due to the many talented, creative survivors who have joined. We Type A people recovered from the original polio with our determination to succeed in life. When post-polio syndrome changed our lives, we were determined to deal with the changes and carry on. And so we have. Along the way we have met many incredible people who had polio. I often say that CEPSPA is a labor of love. The love has outweighed the labor.

We are at 16 years and counting. I hope CEPSPA reaches its 20<sup>th</sup> anniversary and then looks toward its 25<sup>th</sup>. Let's endeavor to gather as long as *we're still here*. Please join us April 27 as we celebrate 16 years of surviving, supporting, caring, achieving, and shining.

Cheryl Brackin, President



## What's Inside THE LIGHTHOUSE:

### CEPSA Business 2-3

- Our Founders
- Our Presidents 1997-2013
- General Meeting Minutes
- Our April Program
- Upcoming Meeting Dates

### Articles 3

- NO MORE EXCUSES!
- Scooter Maintenance Tips

### CEPSA 4-5

- CEPSA Purpose Statement
- S.O.S. Survivors on Search
- Sweet 16 Anniversary Invitation
- Candler Hospital Maps & Info.

### Announcements 6

- Birthdays -Member Concerns
- Condolences -Smart Senior Expo & Health Fair
- Prayer Requests
- Get Well -Quote of the Month

### Articles 7-12

- Jaquelin Perry, MD, Dsc (Hon)
- Ask Dr. Perry- Revised With Jaquelin Perry, M.D.
- Reported by Mary Clarke Atwood

### Home 12-13

#### Modification Project

- BELFOR Donates Barrier-Free Bath
- Home Modification Project  
By Cheryl Brackin
- Accessible Shower Remodel Photos  
Photos by Jacqueline Kelley

### Articles 14-15

- STRESS
- SLEEP DISORDERED BREATHING AND DYSPHAGIA

### Contributions 16

- Contributions Form

**Next Meeting**  
Saturday,  
**April 27, 2013**  
10:30 AM



## ***Our Founders:***

Shirley Carnell,  
Lorraine Frew & Cheryl Brackin

## ***Our Presidents:***

Cheryl Brackin- 1997, 1998, 1999, 2009, 2013

Sandra Bath- 2000, 2001, 2008

Beverly Jarvis- 2002, 2003

Janet DiClaudio- 2004, 2005, 2012

Diane Davis- 2006, 2007

Jim Veccia- 2010, 2011

Coastal Empire Polio Survivors Association, Inc.

## **General Meeting Minutes for March 23, 2013**

Location: Exchange Restaurant

President Cheryl Brackin called the meeting to order at 10:43am and welcomed everyone. She apologized for the late start, but the weather had resulted in several late arrivals.

Lorraine Frew led the Pledge of Allegiance.

The inspiration was given by the Reverend Edward Ellis. His topic was "We Are Never Alone."

### **BUSINESS MEETING:**

**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 Marty Foxx and approved as presented.

**Care Team Reports:** The care team leaders reported concerns about Wakil Carter (Ruth's son), Richard Hall, Bobby Johnson (Patrina's husband), Dick Warden, Harriett Merritt, Delorese Manor, Dot Parkhurst, Janet DiClaudio, Jim Veccia, and Bill Tillman (Cheryl's brother-in-law).

**Old Business:** Lorraine reported that the Skidaway Rotary project for the bathroom modification at her home is complete. The Belfor group has done an excellent job. They will be invited to our 16th Anniversary function along with Tom McGoldrick and the current Skidaway Rotary president. Harvey reported he and Tom are seeking other Rotary clubs in our area for another project for a CEPESA member who needs assistance in home modification.

Marty reported she is still working on updating our member directory. Adrienne will type the final copy for distribution to the members.

**New Business:** Our newsletter editors, Wanda & Carlos, stated that they will prepare a form for the members, explaining the process for obtaining copyright permission for reprinting articles in our newsletter. This will expedite preparation of the newsletter, if members obtain permission prior to submitting an article. The Clases have been

authorized to have 2500 copies of our brochure printed, along with the purchase of holders. We will be placing brochures at various locations, such as physicians' offices, orthotic businesses, pharmacies, etc.

Cheryl reminded everyone that our care team leaders will call in April to talk to members about the 16th Anniversary celebration to be held on April 27th at the Marsh Auditorium at Candler Hospital. Lavonne, Betty, Adrienne, and Terri need a final count by April 22 to order the food for the event.

Adrienne reported her church group handed out 300 copies of the green version of CEPESA brochures over the St. Patrick's holiday with many comments of interest. Harvey brought to the meeting two different copies of articles from *The Rotarian*, including "Polio's Second Act," to share with our members.

**Announcements:** Cheryl reported that Glynn County will hold their annual spring fling function in Brunswick at Mary Ross Park April 13 from noon until 3pm. She asked whether any members from the Brunswick area would be willing to contact the mayor's office to ask if CEPESA can have a display at the event. Penny took the contact information.

Dan shared that what he learned from Corporal Simmons last meeting is real when it comes to scams. He was solicited for funds, followed the directions to avoid this scam, and contacted the FBI.

Betty reported a robbery at a neighbor's home and how they handled the situation.

Deloris reported that her neighborhood watch group has signage that states "If I don't see you, my neighbors will."

Dan gave a report on SCCODI (Savannah-Chatham Council on Disability Issues) and LIFE'S work on the update of the downtown accessibility guide. He stated that LIFE sent out ADA surveys to 140 restaurants, inquiring about their interest in being listed in the guide. We were disappointed to hear that only 7 of the 140 restaurants responded.

The meeting was adjourned at 12:00 pm.

### **PROGRAM:**

We then held a short program of SOS. The topics discussed were bracing, assistive devices, muscle twitching and spasming, and fatigue. Many of our members shared how they have improved their quality of life using creative ways and devices to help them remain independent.

Respectfully submitted,

Michael Dunnermann, Vice-President/Secretary

**Attendance:** Cheryl Brackin, Carlos Clas, Wanda Clas, Esther Simmons, Della Simmons, Michael Dunnermann, Terri Dunnermann, Delores McCall, Marty Foxx, Penny Smith, Ross Smith, Lavonne Calandra, Betty Goff, Sissy Morel, Dan Shehan, Lorraine Frew, Barry Turner, Archie Ivey, Harvey Varnadoe, Adrienne Stallworth, Reverend Edward and Mrs. Ellis.

## Our April Program



Three of our members will be telling their polio stories at this year's 16<sup>th</sup> ANNIVERSARY PARTY. The speakers will be Hattie Evensen, Harriett Merritt and Barry Turner.

Their polio stories will be archived by CEPESA's historian Diane Davis. This year, besides photos of the event, we hope to videotape our speakers and include their stories in our library.

## Upcoming Meeting Dates

April 27, 2013 @ Marsh Auditorium  
May 18, 2013 @ Exchange Restaurant  
June 22, 2013 @ Exchange Restaurant

Future meeting announcement suggested by Michael Dunnermann.

## NO MORE EXCUSES!

A powerchair (not Manual) or scooter is not an instrument of torture. (Although a manual chair can be!) Using a powerchair or scooter will not make you look stupid - at least not as much as pretending you don't need one while taking pain meds and stumbling around, falling down, requiring surgery on hands, elbows, shoulders, knees, etc.

Using a powerchair or scooter will give you more energy because you won't be using all your energy in trying to accomplish the impossible (i.e. - looking like you don't need one). Using a powerchair or scooter will actually be more freeing. You will have the freedom to go wherever you want, without having to have someone chained to you to push you here and there - and then go off to look at something else that interests them and leave you stranded. (Been there, done that!)

Using a powerchair or scooter will relieve the strain on overtaxed shoulder muscles and joints that were never meant to be walked on in the first place, thereby eliminating much of the unnecessary surgeries which, by the way, will not last unless you change the way you do things. You may also find that you don't need as much or any of the pain meds.

Using a powerchair or scooter will show that you are winning the battle! But you need to define your battles. You already had polio. No way to change that. You are having postpolio sequelae. Another done deal. These are battles people frequently think that they need to fight against, but there is no way to win here. It's happening. Live with it. But the battle you can win is the battle for

independence! You can be your own person again. It has been said, "Fight only the battles you can win". Living life on your own terms is possible only if you have the stamina, the balance, and the heart for it. We all have the heart for it. . . we are polio survivors! What we don't have are the balance and the stamina. A powerchair or scooter can help.

Do you always walk to the grocery store 5 miles away? Do you walk to work? To Church? Of course not! You use the technology available to you - a car or public transportation. Do you mix your cake batter with a spoon? Or do you use an electric mixer? These are devices that help to make our lives easier. So are powerchairs and scooters. You are not giving in. . . you're stepping up to an easier way of doing things. And Boy! Are they ever fun!

If you are thinking about it, it is probably past time to do it. And the sooner you start using a power mobility aid, the longer you might retain the ability to walk and the easier it will be on your arms and shoulders in the long run. I wish you well.

### Florida East Coast Post-Polio Support Group Editor's

**Note:-** As most of you know, I use a scooter - in fact, I'm on my third Electric Mobility Rascal. Whenever I see a polio (or other mobility impaired individual) that should be in a powerchair or scooter I cringe. If I question them as to why they're not using a powerchair or scooter, they're answer is usually that they don't need it - they aren't that bad. Hopefully, this article will help some realize that using such an aid will open many doors that have been closed to them - such as going to the mall, going to theme parks, taking a "walk" with the grandchildren.... Please, if you need a powerchair or scooter, look into getting one.

Reprinted from SPIRIT, PPSG, Southeastern, WI, June 2004. and Florida East Coast Post-Polio Support Group newsletter, Nov-Dec, 2005.

Reprinted from "Library of Articles," Central Virginia Post-Polio Support Group, Richmond, VA.

## Scooter Maintenance Tips

Mobility Project Co-Chair Richard Graham suggested that those that own a scooter should recharge their scooter batteries once a week, even if you are not using your scooter on a regular basis. After recharging your batteries, your scooter should be turned on and moved around the house or garage. This keeps all parts in working order and prevents the tires from "flattening."

Richard also gave another tip to prevent your tires from getting a flat spot. You may need help with this suggestion. Sandwich the tires between pieces of 2 X 4's to get the scooter to lift slightly off the ground.

Newsletter Co-Editor Carlos Clas adds that he sets his cell phone alarm to go off once a week to remind him to recharge his scooter batteries.



*Shining Light on Post-Polio Health*

## PURPOSE STATEMENT

The purposes of CEPSA are:

- *Locate polio survivors and provide them with information about post-polio syndrome;*
- *Give referrals for medical and emotional assistance;*
- *Counsel as needed or requested;*
- *Educate the members, their families, the medical community, and medical and personal caregivers about post-polio syndrome;*
- *Provide financial support to polio survivors for necessary equipment or medical care not covered by insurance, or for times of personal crisis, or other extenuating circumstances, depending on availability of funds with the approval of the Executive Board;*
- *Promote public awareness of polio, post-polio syndrome, polio immunizations, global polio eradication and local accessibility issues;*
- *Promote social welfare, education, and fellowship through activities such as tours, holiday dinners, field trips, conferences, seminars, and workshops;*
- *Raise, receive, use, hold, and apply any contributions, bequests, endowments, or other proceeds to carry out the general purposes.*

### S.O.S.

#### *Survivors on Search*

Many polio survivors are experiencing new problems associated with the polio virus that was contracted forty to fifty years ago.

Coastal Empire Polio Survivors Association is searching for polio survivors to offer vital information about "The Late Effects of Polio."

**If you are a polio survivor, or if you know someone who had polio, please contact CEPSA.**

*Thank you for your help.*

# SWEET SWEET SWEET 16

You're  
Invited to  
CEPSA's

## 16th

# Anniversary Celebration.

*When* : Saturday, April 27, 2013

*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, Hattie Evensen, Harriett Merritt and Barry Turner, 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.

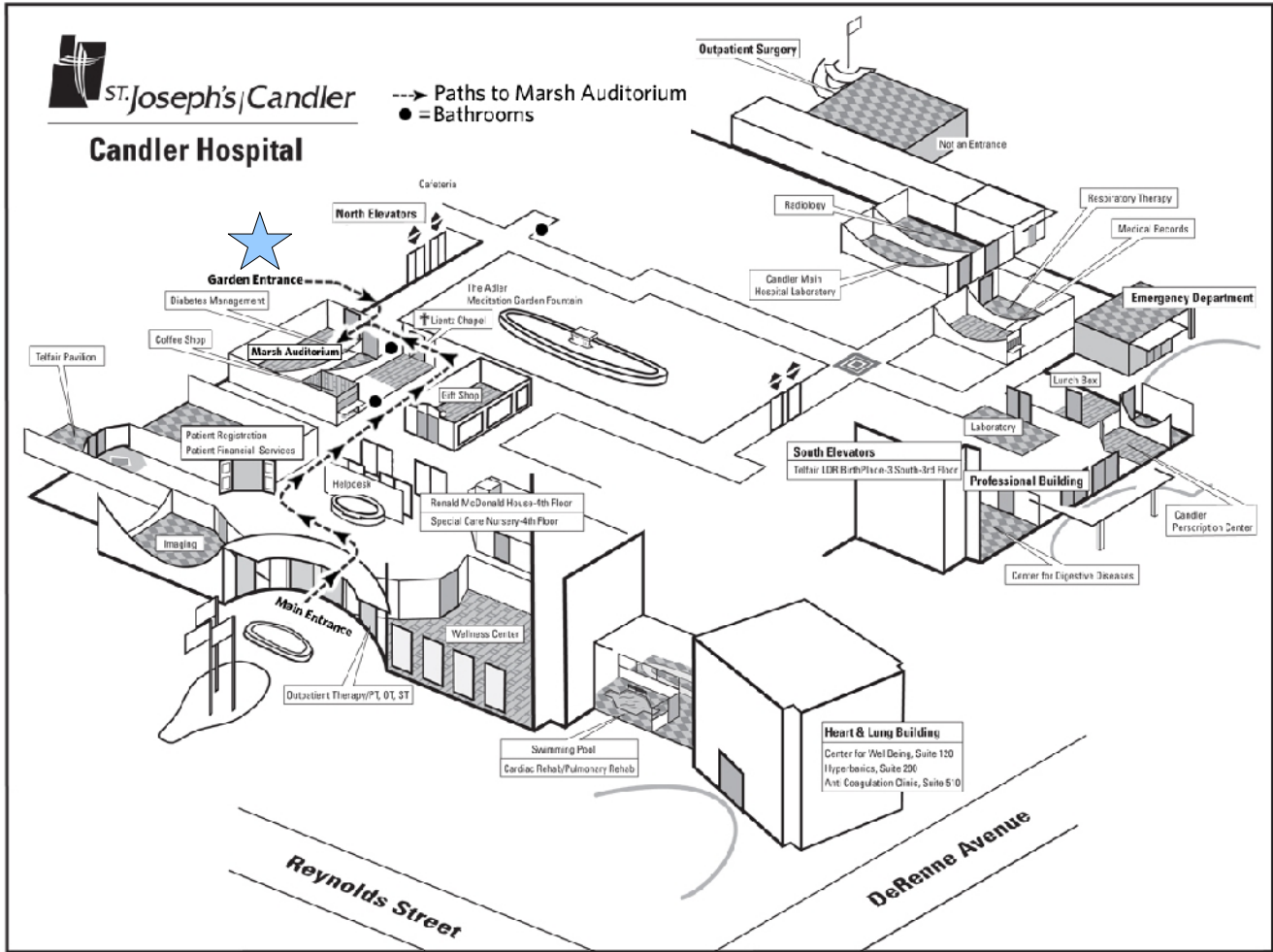
These ladies have done an outstanding job every year. We thank them for all their hard work.

**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

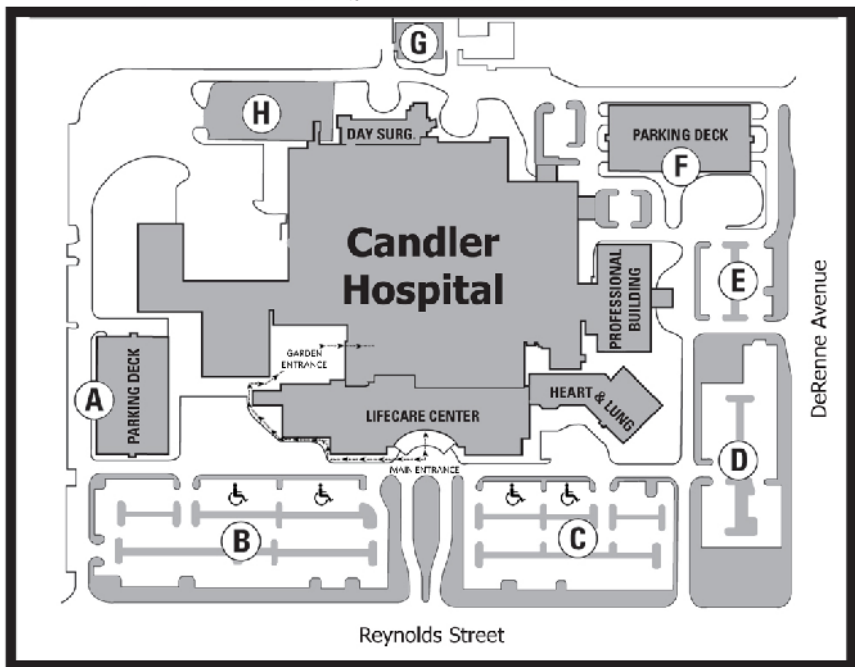


AD20124 (7/10)

Candler: Parking Areas A thru H and Aerial View

★ 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 2 security officers on duty April 27. 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.



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

## Happy Birthday



### April

Fred Davis - 2  
Tom Newcomer - 2  
Sissy Morel - 6  
Marty Foxx - 8  
Stuart Robinson - 27

### May

Bob Parkhurst - 6  
Lucille Robinson - 13  
Vivian O'Kelley - 14  
Allen Igou - 17  
Wanda Clas - 19  
Dale Merritt - 26  
Richard Graham - 31

## Member Concerns

Janet DiClaudio, Betty Hope, Bobby Johnson,  
Delorise Manor, Harriett Merritt, Dot Parkhurst,  
Dick Warden & Idella White

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



## Condolences

It is with great sadness that we say goodbye to one of CEPESA's inactive members, Glenda F. Walker of Jesup. Glenda passed away on March 8, 2013, at Wayne Memorial Hospital.

Glenda was affectionately known as "Faye." She was a member of St. James Missionary Baptist Church, where she served as a choir member, assistant Sunday school superintendent, and member of the mission amongst various other committees of the church.

She always expressed how she longed to join us at the monthly meetings, but was unable to travel so far. She enjoyed receiving the newsletter and her Care Team calls. Our condolences to her family. To read more about Glenda, visit:

<http://www.legacy.com/obituaries/coastalcourier/obituary.aspx?pid=163620109#fbLoggedOut>

CEPSA would like to offer our condolences to members Dot and Bob Parkhurst, on the loss of Dot's sister. Please keep them and their family in your prayers.

## Smart Senior Expo & Health Fair

The Smart Living Expo for seniors returns. Join St. Joseph's/Candler for the Coastal Empire's largest and most unique senior expo and health fair featuring free health screenings and activities. It is free and open to the public.

**When:** Friday, May 10, 2013

**TIME:** 9AM - 1PM

**Where:** The Armstrong Center  
1195 Abercorn Street  
(across from Savannah Mall)

Event announcement suggested by Cheryl Brackin.

## Prayer Requests

Dear Friends,

I am asking for your prayers for my brother-in-law Bill Tillman. He came through gall bladder surgery well today at Memorial Health. However, Bill appears to have metastatic colon cancer. This will be treated with chemotherapy, no surgery. We are hoping this affords him some more time with us. Dr. Patrick Hammen, his surgeon, is an outstanding, caring physician. He was forthcoming with Bill, as he should have been. My brother-in-law jokes often and asked the dr. whether the chemo would cause him to lose his hair. Bill is essentially bald!! This kind of spirit should help him during many difficult days to come. Bill was like a son to my mom and helped her so much during her last years. He got my lunch every day when I stayed with him and Sheila while recovering from my knee surgery in 2008. Our family will appreciate your prayers for Bill. Thank you and God bless.

Fondly,  
Cheryl

From an e-mail from Jim Veccia to all CEPESA members. 20 March, 2013.

Dear Editors,

I spoke to Patrina Johnson today. Her husband Bobby had an amputation of half of his left leg, due to diabetes complications, on Feb. 24 at Candler. He was there 3 wks., including 2 for rehab. Bobby is resting at home and will be fitted with a prosthesis later. He is determined to walk again, using 2 prosthetic legs. Please ask CEPESA members to remember Bobby and Patrina in their prayers.

Thanks.  
Cheryl

From an e-mail from Cheryl Brackin to Carlos & Wanda Clas. 29 March, 2013.

## Get Well

Our best wishes for a complete and speedy recovery to Wakil Carter, son of CEPESA member Ruth Parham. Wakil is recovering from back surgery. Get Well Soon!

Get well wishes to Thad Brackin, brother of CEPESA President Cheryl Brackin. Thad is recovering from kidney stone surgery. We wish him a full recovery.

## Quote of the Month



"The probability that we may fall in the struggle ought not to deter us from the support of a cause we believe to be just; it shall not deter me."

-Abraham Lincoln (1809-1865)

16<sup>th</sup> President of the United States of America

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.

Dr. Jacquelin Perry died at her home in Downey, California, on March 11, 2013 according to The New York Times obituary that was published on March 23, 2013 as announced by the Rancho Los Amigos National Rehabilitation Center.

Please visit the link below to read her obituary in The New York Times.

[http://www.nytimes.com/2013/03/24/health/dr-jacquelin-perry-who-aided-polio-victims-dies-at-94.html?\\_r=1&.>](http://www.nytimes.com/2013/03/24/health/dr-jacquelin-perry-who-aided-polio-victims-dies-at-94.html?_r=1&.>)

Link from an e-mail from Jim Vecchia. 25 March, 2013.



## Jacquelin Perry, MD, DSc (Hon)

**Born:** May 31, 1918  
**Died:** March 11, 2013



### Major Contribution:

Known among her peers as the Grande Dame of Orthopaedics, Dr. Jacquelin Perry was one of the first ten women to be certified by the American Board of Orthopedic Surgery. She broke new ground in laboratory research by becoming the country's foremost expert on gait analysis. She is co-author, with Judith Burnfield, of *Gait Analysis: Normal and Pathological Function*, the classic text on gait analysis.

In the early 1950s, she jump-started the surgical program for post-poliomyelitis patients at Los Angeles' Rancho Los Amigos Medical Center. The medical staff was looking for ways to provide stability for the more significantly disabled polio patients who had paralysis of the neck and trunk. Recognizing that bracing was not adequate, she, along with Dr. Vernon Nickel, pioneered the use of halos for spinal surgery and rehabilitation.

Perry's contributions to the body of knowledge of understanding human movement included studying all forms of functional assists from canes, to crutches, braces and wheelchairs. She compared the effectiveness of various forms of bracing and prostheses, total joint replacements, resection arthroplasty and other surgical interventions. She also studied the effects of injury in both professional and recreational athletes.

### Other Information:

**Brief Bio:** Jacquelin Perry was born in Denver, Colorado, but was raised in Los Angeles, California, the only child of a clothing-shop clerk and a traveling salesman. She recalls, "I knew at about age 10 that I wanted to be a doctor. I read every medical book in the Los Angeles library." (1) She received her bachelor's degree in Physical Education at the University of California, Los Angeles in 1940. Next she joined the army and trained to be a physical therapist, receiving a certificate from Walter Reed Army General Hospital in Washington, D.C.

She completed a two-year assignment at Hot Springs, Arkansas, and that military experience gave her a strong background in poliomyelitis and arthritis. After World War II, she used the G.I. Bill to study medicine and became the first woman orthopaedic surgeon to graduate from the University of California, San Francisco. Like many orthopaedic surgeons, she was skilled with hand tools and improvised and built many of the rehabilitation devices she used with her patients.

In a published profile in the *American Academy of Orthopaedic Surgeons*, Dr. Perry said,

*"It was definitely not a field for women back then. People said it was too strenuous. Too mechanical. My medical school class had 10% women - seven out of seventy-six, pretty good numbers for those days. Orthopaedic surgery wasn't very popular in those days, it was mostly braces and buckles, not the surgical specialty it is today."* (2)

In 1955, she joined the medical staff at Rancho Los Amigos and was Chief of the Pathokinesiology Service for 30 years. She once stated that her polio experience at Rancho broadened her medical experience (and that of others) because they developed a team concept of patient care; nurses and therapists were encouraged by the physician to take responsibility for evaluation and treatment planning. (3)

She was honored with "Woman of the Year for Medicine" in Southern California by the *Los Angeles Times* in 1959.

When polio patients started coming back to her with post-polio symptoms in the late '70s, she counseled them not to push themselves but to modify their lifestyles and implement energy conservation techniques in order to accommodate their new reality. In an article called [General Information Letter for Polio Survivors: Why are "old polios" who were stable for years now losing function? What should they do about it? SPANISH](#), Perry advises, "Be an "Intelligent Hypochondriac" - Listen to your body and adopt a program that avoids the strain."

Her publications, noted for their rigorous scientific standards, reflect her particular concern for patients with many conditions, such as multiple sclerosis, cerebral palsy and stroke, and individuals with spinal cord injury and amputation. In addition to the well-known gait textbook, she co-authored more than 400 peer-reviewed papers and 38 book chapters.

Her 50-year career is reflected in the many awards and teaching positions she has held. She founded the Scoliosis Research Society and was a board member of numerous professional societies. Credentials for Dr. Perry include board certification in Orthopaedic Surgery, membership of the American Academy of Orthopaedic Surgeons, American Orthopaedic Association, American Institute for Medical Biological Engineering, Western Orthopaedic

Association, California Medical Association, Los Angeles County Medical Association, American Physical Therapy Association (honorary lifetime membership), Scoliosis Research Society (Emeritus), LeRoy Abbott Society, American Academy for Cerebral Palsy and Development Medicine, American Academy of Orthotists and Prosthetists (honorary membership), Ruth Jackson Society and Gait and Clinical Movement Analysis Society.

Dr. Perry's numerous awards, accolades, professional activities and visiting professorships have influenced many outreach programs for female students in the fields of orthopaedic surgery, physical therapy and mechanical engineering (such as the "The Perry Initiative" and the *Jacquelin Perry, MD, Resident Research Award*).

The *Jacquelin Perry Neuro-Trauma Institute and Rehabilitation Center at Rancho Los Amigos* was dedicated in 1996 in her honor. At the ceremony she remarked, "It amazes me that I should be honored for doing the very things I enjoy."

In 2000, PHI honored Dr. Perry at its 8th International Post-Polio and Independent Living Conference held in St. Louis, Missouri. She, along with Dr. Augusta Alba, was recognized for her dedicated years of supporting polio survivors by combining her medical expertise with practical advice.

She stopped performing surgeries in the late 1960s as the result of a brain artery blockage, but continued doing research focused on gait. Perry, who later developed Parkinson's disease, continued practicing into her nineties. She died in March of 2013 at the age of 94 (see [Los Angeles Times obituary](#)).

1. From text of Honorary Award presented in June 2000 by PHI.
2. From "[Rancho's Angel](#)" in *Moving Stories: 75 Years of Orthopaedics*.
3. From text of Honorary Award presented in June 2000 by PHI.

#### **Description of publications:**

See "Major Article" tab

For a full listing of her Dr. Jacqueline Perry's life work see her [Curriculum Vitae](#).

Hear an [audio clip](#) of Dr. Perry being interviewed by the *American Academy of Orthopedic Surgeons*.

[2006 interview with Dr. Perry](#) by Neena Bhandari of *India Voice*

*May 2012/Carol K. Elliott & Joan L. Headley/Post-Polio Health International*

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Reprinted from Polio Place ([www.polioplace.org/people/jacquelin-perry-md-dsc-hon](http://www.polioplace.org/people/jacquelin-perry-md-dsc-hon)) with permission of Post-Polio Health International.



# Ask Dr. Perry - Revised

## With Jacquelin Perry, M.D.

Reported by Mary Clarke Atwood  
Editorial assistance by  
V. Duboucheron, J. Perry, M.D.

*Rancho Los Amigos Post-Polio Support Group*  
*Newsletter-May 2006*  
**Updated March 2006**

Our thanks to Dr. Perry for so graciously taking the time to review and update these responses. Since retiring after 40 years of dedicated, full time county service, polio specialist Dr. Jacquelin Perry continues her work at Rancho but in a new capacity -- as a volunteer consultant. The Rancho Los Amigos Post-Polio clinic continues to be a source of excellent care each Friday afternoon due to the commitment of two other excellent physicians. Dr. Sophia Chun is the current chief of the clinic; her medical training includes both internal medicine and rehabilitation. Dr. Vance Eberly is an orthopaedic surgeon. Both attend the clinic regularly and Dr. Perry is there frequently. Dr. Perry also volunteers as a medical consultant to the Rancho Los Amigos Pathokinesiology Laboratory. She no longer gives lectures.

**Question 1.** What is the natural progression of post-polio syndrome? Will a person return to the same degree of paralysis that was experienced at onset?

**Answer:** When focusing on the natural progression of PPS it is important to understand that muscle function depends on three systems:

1. Control from the brain
2. Sensation from the periphery
3. The lower motor system from the spinal nerve cell (anterior horn cell) down to the muscle.

The third system is the most important for people with PPS because if you lose the nerve, you lose the muscle. We talk about muscle weakness, but polio is actually a nerve disease that damaged or killed anterior horn cells. This makes a lot of difference in terms of exercise, etc.

**Acute:** During the acute phase of polio some spinal nerve cells died while others were injured but later recovered. Some people had paralysis but others did not. The effects were like spatter paint. If you had a lot of "paint" you had a lot of damage, while others were

just touched lightly. But all survivors were left with a damaged neuro-muscular system.

**Recovery:** Recovery from polio entailed all three methods of recovering function:

- **Neuro recovery**  
Between 12% - 91% of the nerve cells that were injured by the poliovirus recovered.
- **Axon sprouting**  
New branches of the remaining nerve cells were sent out to adopt the orphaned muscle fibers. The result was that each nerve was then doing 50% more work, or even up to four times as much as normal.
- **Hypertrophy**  
The muscles enlarged themselves up to about 40% so they could increase function.

It is not known how much a survivor's recovery was due to spontaneous nerve generation, nor how much could be credited to patching by the axon sprouting, nor what amount was due to hypertrophy. Upon recovery polio survivors had a random disability in regard to the amount of paralysis. The amount of muscle weakness a person had was pure chance; it depended upon the amount of poliovirus a person had and where it went. Some survivors remained paralyzed, while others looked or felt normal although they were not.

**Research:** During the 1940s Bodian traced the poliovirus in the motor nerve cells of monkeys. He found that polio, a systemic disease, affected 95% of these cells by either injuring or destroying them. Research confirms that there is some obvious weakness as a result of polio:

- Agre found that polio survivors with no current symptoms had only 80% of normal muscle strength. Symptomatic survivors had 60% or less muscle strength compared to the normal group.
- Following a four-year study Grimby reported a normal 2% - 5% loss of muscle strength in asymptomatic polio survivors, but for symptomatic survivors this loss may be as high as 13%.
- A study by Grimby confirms that weaker muscles work longer and twice as hard.
- An electromyographic study by Dr. Perry also confirmed that weaker

muscles work longer and twice as hard.

This research says that it is necessary to protect an overused muscle system. The muscles that are grades 3, 3+, and some 4s are getting all the exercise they can tolerate. In order to maintain this function these muscles must be protected from overuse. Dr. Perry added, "New damage is prevented or curtailed by being active, but avoid getting tired. When fatigue begins, STOP and rest. Two 20-minute rest periods a day preserves one's endurance."

Now: For many, many years polio survivors have been working with a damaged neuro-muscular system that keeps working harder than ever to meet normal demands. We need to appreciate the fact that each anterior horn cell innervates several hundred muscle fibers and the surviving horn cells have been doing 50% more work than normal. Plus it appears they don't like being overworked!

Because of this overuse of the neuro-muscular system, new weakness is now developing. Survivors may develop new weakness not only in "polio" muscles but also in other muscles that did not seem to be involved during the acute phase.

Although the amount of weakness a polio survivor develops in later life depends upon the original involvement, age is also a factor. Anterior horn cells do not have infinite durability -- they begin aging at about 60 years of age. So polio patients aged 70 and up have a natural weakness just from age that needs to be appreciated and put in perspective also.

**Question 2.** Do you know of any research on treatments for PPS?

**Answers:**

- **Mestinon:** There was a six-center study of the drug Mestinon (pyridostigmine) in 126 patients. Mestinon acts at the nerve-muscle junction by changing the chemistry and making the connection last longer. For many years this drug has been used for myasthenia gravis patients. Since Grimby's research has shown that polio survivors can overuse the nerve-muscle junction, the use of Mestinon for some polio survivors makes sense to Dr. Perry.
- In this 1995 Mestinon study, Dr. Daria Trojan reported that there was trouble getting statistical significance, but the best correlation between Mestinon and relief versus the placebo occurred in

subjects who had 25% or less normal strength, i.e. muscle grades 3+ and down. Dr. Perry believes Mestinon has a role for those who are quite weak, but for people with grade 4 muscles and up she has observed no improvement with its use.

- **Anti-inflammatory Drugs:** These medications have been Dr. Perry's mainstay because the first reaction to muscle overuse is inflammation. These drugs take away the added insult from having overdone but they are not pure pain medicines. Dr. Perry does not use pain medications per se for PPS because they only mask a person's overuse and do not help that problem. She wants patients to control their lifestyle and not overdo and thus avoid the pain of overuse.
- **Growth Hormones:** These drugs have been found to relate more to muscle function than to nerve control. They seem to parallel function rather than control function. No significant changes have been found for polio survivors.

**Question 3.** Are you familiar with electro-stimulation for polio survivors?

**Answer:** The answer is yes and the answer is no. The easiest way to stimulate a muscle is to use one that has a nerve. Therefore, this involves the nerve-muscle junction. Electro-stimulation has been tried on a few polio survivors at Rancho with no affect; Dr. Halstead, a polio survivor affiliated with National Rehabilitation Hospital in Washington, D.C., tried it on himself with no affect; several of Dr. Perry's patients tried it at Dr. Pape's office in Canada with no affect. So electro-stimulation is not an answer. Post- polio patients' problems are with the nerves.

**Exercise:** Some researchers in other parts of the country favor exercise for certain polio survivors. I observed that their research has been done in parts of the country that have bad weather -- so their subjects already have about 3 months disuse due to climate. Here in Southern California we do not have disuse because of bad weather. If disuse of muscles does exist, then exercise may be needed. But if there is no disuse, such as here in Southern California, exercise is not indicated.

**Question 4.** Can trauma be a trigger for PPS?

**Answer:** The answer is yes. Following an acute injury

there is a period of disuse during recovery. Up until the time of injury a person's strength has been built up very gradually. There is an old saying that says, "If you can lift a calf every day, when you become an adult you can lift a cow. But don't ever stop." This phrase is saying that if you got a very small amount of increased exercise on a regular basis (as the calf got larger) you built up yourself gradually. But don't ever change the model. As soon as you stop, there is no way you can exercise that gently anymore. It is very difficult to recover on a therapeutic basis after that. Once there has been an injury the model has been changed.

**Question 5.** Does spinal stenosis occur earlier for polio survivors?

**Answer:** Spinal stenosis is the thickening of bone around the spinal canal. It does occur in natural society but it is not very common. I have not seen any PPS patients with spinal stenosis.

**Question 6.** Could you give us some tips for putting less stress on our upper extremities?

**Answers:**

- Problem 1: Shoulder pain develops in crutch users.  
What does a crutch do? It supports body weight. The more weight, the more it goes on your hand, elbows, and shoulders. When the normally powerful shoulder depressors (pectoralis major, etc.) wear out, the shoulder takes the strain and the supraspinatus tendon gets impinged (pinched). This impingement cannot be prevented. Pain indicates it is time to ride -- in a wheelchair or scooter if appropriate.
- Problem 2: Upper arm pain when reaching overhead.  
Reaching overhead uses two muscle systems. A person can avoid overhead reaching by using a reacher when necessary and by not placing things above the shoulders. Find other activities that do not involve shoulder use.
- Problem 3: A person's arm dropping away from the socket (usually about 1/4 - 1/2 inch).  
Slings don't usually work well because they hang from your neck. I prefer to use a gunslinger apparatus to help support arm and shoulder. A gunslinger

is a device that rests on the hips/pelvis area and has one or two attached pieces to support the forearm(s).

Some patients use a fannypack under the arm for support.

- Problem 4: Shoulder and neck pain when working at a desk.  
When working at a desk, do not lean forward to do your work. Instead, try to lean back ten degrees so gravity is helping your muscles. Bring your work to you.

There are three things a person can do to relieve the strain on the upper body muscles:

1. Eliminate reaching
2. Support the arms
3. Break up activities

**Advice:** Listen to your body. Feel the aches and pains. Then do something about it. **"Be an intelligent hypochondriac!"**

**Question 7.** When should we use cold packs or hot packs?

**Answer:** Cold for 5 minutes or less is good. It breaks up the edema formed by overuse. Then follow with heat for 10 minutes and REST a while.

**Question 8.** Are you sending any PPS patients for acupuncture?

**Answer:** I am not sending anyone for acupuncture although some patients are trying it and getting help. It is not going to do any harm. The reason I do not prescribe it is because I do not have any indication of whether it will help or not help. When I make a prescription I would like to know the outcome.

**Question 9.** Can PPS be part of a weakening heart muscle?

**Answer:** No, PPS cannot be part of a weakening heart muscle. The muscles and nerves to the heart are a different system so there is no direct connection to PPS.

A person can be deconditioned by not being active, but if you are not strong enough to be active your heart does not have to be that conditioned. So don't worry about it. Just don't get fat and do avoid cholesterol!

**Question 10.** How can a polio survivor control muscle twitching and/or cramping?

**Answer:** Muscle twitching is a sign of overuse. It can

happen to anyone, not just people with PPS. Cramping is also a sign of overuse. A polio survivor needs to change his lifestyle to avoid overuse of muscles. [Conserve it to preserve it.]

**Question 11.** What are your thoughts on hip or knee replacement surgery?

**Answer:** For an arthritic hip, total joint replacement is just fine if you have the muscles to control it. A polio survivor needs to have about grade 3+ hip muscles for this surgery to be successful. Otherwise the hip will dislocate.

The knee is simpler to handle because it can be put in a brace since it is a tubular structure. But there is no brace for a hip.

**Question 12.** How can sleep problems be helped?

**Answer:** A study on sleep disorders compared people with PPS to average people. Both groups had the same problems -- restless legs, etc. I suggest that, before going to bed, people get themselves comfortable, warm, and perhaps take 2 Advil (or something like that) to get rid of the aches and pains. If a person awakens in the middle of the night, it may be helpful to get up and start again. Half the world has trouble sleeping all night. This is not unique to polio.

If a polio survivor has been diagnosed with sleep apnea it is probably related to breathing or swallowing problems from PPS.

**Question 13.** Is there any connection between polio and meningitis? When I was a baby my parents were told I had meningitis. Several years ago a doctor told me I never had meningitis but I had polio.

**Answer:** Meningitis is an inflammation of the coverings of the spinal cord and brain. Polio is an infection of the anterior horns of the spinal cord. The inflammatory reaction also involves the meninges. At one time it was called polio-encephalo-meningitis. It was actually an involvement of the whole system. The main way of identifying polio was with a spinal tap. If it got into the anterior horn cells it was called polio. There are a lot of neurological problems that are not highly defined, but can be identified by lesions revealed during autopsy.

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## BELFOR Donates Barrier-Free Bath



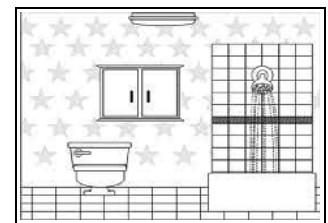
BELFOR Savannah Estimator Jason King was recently honored by the Rotary Club of Skidaway for his generous and creative bathroom renovation services that provided relief for a local woman with post-polio syndrome.

Jason learned that a mobility-impaired local homeowner could no longer use her bathtub, despite the installation of a grab bar. In addition, she was unable to afford accessibility remodeling. A team from BELFOR Savannah removed the standard, difficult to use bathtub and installed a new easy access walk-in bath and shower combination.

Reprinted with verbal permission from Belfor Savannah's General Manager, Jason King. <<http://www.belfor.com/en/USA/Georgia/Savannah-Georgia.aspx>>.

## Home Modification Project

by Cheryl Brackin



Another CEPASA first!! The bathroom modification project at the home of Lorraine Frew has been completed. CEPASA collaborated with the Rotary Club of Skidaway, which obtained the services of Belfor Savannah. Belfor USA is a worldwide leader in disaster recovery and property restoration. The local office is in Garden City. They provided the materials and labor to convert Lorraine's bathtub space into an accessible walk-in shower. The work began January 14 and was completed approximately two months later. A 2-3-day project required much longer due to original construction mistakes in the home. Lorraine happily gave updates on the work at our February and March CEPASA meetings. She praised the Belfor staff for their professionalism and courtesy from the first day. She particularly mentioned General Manager Jason King and Tom Greve, who directed the job and participated at the site. Lorraine stated "It is just wonderful," regarding her new shower.

Our support group is very pleased with the finished results and so glad that Lorraine, a CEPASA co-founder, can maintain her independence and safety in her home. We salute Rotary for its interest in polio survivors experiencing the late effects of polio. We salute the Belfor Company for its compassion and willingness to go to extraordinary lengths on this project.

## Accessible Shower Remodel

**CHALLENGE:** Convert a regular bathtub into an accessible shower.

**SOLUTION:** Completely remove the bathtub, bottom half of surround, concrete slab, and install a roll-in shower complete with accessible shower seat and beautiful new tile.



Photos courtesy of Jacqueline Kelley.

# STRESS

Stress is anything in our lives that we find challenging, demanding, or threatening. With this in mind, it is easy to see how facing the possibility of, or experiencing the late effects of polio can cause stress. A contributing cause of PPS is emotional stress. Stress may be inhibiting the brain's reticular activating system resulting in increased levels of fatigue.<sup>12</sup> Thus, it is vital that polio survivors learn to control and cope with the stress in their lives. 48



Everyone experiences stress. As human beings, we have evolved to deal with stress in a physical manner. But the late effects of polio are not physical things which you can strike out against. The stress evolves from dealing with a chronic problem. You start to experience many different feelings, such as:

*fear* of the late effects, that you may go back to how you were in the initial illness,

*anger*, that it is happening to you, again, for a second time!

*worry* that you may need to ask for more help,

*denial* this is not really happening to you, there is no change in your polio-related status,

*guilt* about changes in lifestyle, especially those that might demand more from others,

*depression* concerning the negative way the late effects are affecting you,

and *concern* that you will continue to have the courage to cope, the will to fight on.

To effectively deal with stress you must fully understand the problem. This resource booklet

(<http://www.easterseals.ns.ca/wp-content/uploads/2009/06/Polio-Nova-Scotia-Late-Effects-Guide-for-Polio-Survivors.pdf>) will help to educate you on the late effects but *it is up to you to do it*. Seeking help by reading books, watching video programs on coping with stress, perhaps seeing a psychologist will aid you in this task.

Many polio survivors are overachievers, so have the courage to cope is not a new experience. You must remember that the late effects of polio is relatively new. It will take work by you, your family and friends, and your attending health professionals, to help you cope with the late effects of polio.

**Caution:** Some of the mood uplifting drugs (anti-depressants) may enhance fatigue and, like alcohol should be avoided.

## Steps in learning to accept the late effects of polio.

- Period of mourning. This is a normal experience. It is during this time that you question many things and feel the strongest emotions. Emotions such as anger, fear, depression, denial, and resentment, are normal reactions in the process of coping with the changes at this time.
- Devaluing physique. It becomes important to place less emphasis on your physical appearance. Doing this will allow you to accept the use of orthotics and other aids more readily. And, more women today wear trousers, and more wear so-called sensible shoes! Down with fashion, up with comfort!
- Enlarge your scope of values. Focus your attention on the things that you can do and not what you are unable to do. Find things that you can do, while letting go of others. Find new hobbies or new ways of doing your current activities.
- Uphold asset evaluation. Do not compare yourself to everyone else. Setting your physical standards against a person not experiencing the late effects may give you very unrealistic goals. You are valued for who you are, not for what you do. 26



"Not another sleepless night!"

## SLEEP DISORDERED BREATHING AND DYSPHAGIA

Sleep disorders in the form of breathing problems due to weakness of respiratory muscles, and dysphagia can be very dangerous if not constantly monitored or treated. A referral to a pulmonologist, at least a respiratory therapist is indicated to determine the most appropriate treatment for you. If you experience respiratory problems and have a history of recurrent respiratory infections, an annual flu vaccine and Pneumovax is recommended. 6, 9

Sleep disordered breathing can be treated with nasal supplemental oxygen alone, or with nighttime ventilatory assistance, such as use of a chest cuirass. For some a continuous positive airway pressure ventilator will allow sufficient oxygen to be taken in, preventing the headaches associated with sleep apnea. Sleep apnea may also be treated with drugs. Tracheostomy should be avoided if possible. 6

You should quit, at the very least cut down on any **smoking**. Smoking increases breathing difficulties, and causes other respiratory problems, such as emphysema and bronchitis. Try a nicotine patch, smoking cessation programs, herbal cigarettes that contain neither tobacco or nicotine.

When visiting a doctor or dentist, make sure you inform them that you are a polio survivor, and of any late effects of polio that you may be experiencing. Anaesthetics, pain killers, and muscle relaxants used during and after surgery or oral work can worsen episodes of sleep disordered breathing, dysphagia, and other late effects. Sleeping pills should be avoided as they can increase breathing difficulties during the night. Try out other ways of inducing sleep, such as a tape of relaxing music, etc.

A referral to a speech-language pathologist is indicated for dysphagia. This professional will help in identifying simple rehabilitation techniques to assist in management. 16, 9 Ensure you and others close to you know how to do the *Heimlich maneuver*.

### Guidelines for Treatment of Dysphagia 16, 9

- If you have difficulty swallowing, get a referral from your family physician for a modified barium swallowing study. This will determine the cause of the problem.
- Something as simple as tilting your head while eating may help to relieve swallowing difficulties.
- When fatigued, avoid eating. Fatigue exacerbates swallowing difficulties.
- Monitor your intake to identify foods that aggravate your problem.
- Don't talk while eating; take small mouthfuls; cut small items like meat.
- Be reassessed at regular intervals. This will determine the effectiveness of treatment or coping programs.
- Measures of pressures and flow rates during swallowing will help determine your specific weaknesses. 16

*All polio survivors experiencing late effects, and especially those with respiratory or swallowing problems should be registered with, and wear a **Medic alert™** bracelet.*

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Reprinted with Permission from Easter Seals of Nova Scotia. Please visit the following link to read the entire booklet. <<http://www.easterseals.ns.ca/wp-content/uploads/2009/06/Polio-Nova-Scotia-Late-Effects-Guide-for-Polio-Survivors.pdf>>.

## **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
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Please complete this form and mail it along with your check to: **CEPSA, Marty Foxx**

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Are you a relative or friend of a CEPSA member? \_\_\_\_\_

Name of member

*Thank you for your support and encouragement.*



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*Shining Light on Post-Polio Health*

**CEPSA's next meeting is on  
Saturday,  
April 27, 2013  
10:30 AM  
in the Candler Hospital  
Main Building, first floor,  
Marsh Auditorium.  
5353 Reynolds Street  
Savannah, GA 31405**

