



THE LIGHTHOUSE

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

April, 2012 Newsletter

www.coastalempirepoliosurvivors.org

Vol. XV, No.4



The President's Message...

Happy 15th Birthday CEPSA. We have a lot to celebrate. Our history is included in this newsletter. Some of the highlights that I remember are:

- The first meeting held in the Gastroenterology Suite on the first floor of the Candler Professional Office Building in 1997.
- The first speaker Dr. Paul Peach who presented a seminar about "The Late Effects of Polio."
- The first newsletter written and printed by Beverly Jarvis.
- Yard sales that were held for fundraising in our early years. We worked hard and had a good time. One was held at Marty Foxx's home.
- The 2004 Year of Polio Awareness Exhibit at the Oglethorpe Mall and all the members who volunteered and showed up to assist.
- CEPSA's incorporation in 2004, which led to our being approved as a 501(c)3 nonprofit organization in 2005, by the Internal Revenue Service. This was the Executive Board's first and only try.
- The excellent programs presented by experts in medicine, allied health, Social Security, chaplaincy, and long-term care insurance to name a few.
- The Executive Board meetings held at the Living Independence for Everyone, Inc. (L.I.F.E., Inc.) office on Travis Street. We appreciate their cooperation and support.
- The Physical Therapy seminar in 2011 presented by Dr. Holly Wise with the Coastal Post-Polio Clinic in Charleston S.C.
- The Heel-to-Toe for Polio walkathons held in 2009, 2010 and 2011. We raised funds with five Rotary clubs in South Carolina to meet a challenge from Bill Gates to eradicate polio worldwide.

We will be celebrating the anniversary of our birthday on Saturday, April 28, 2012 in the Marsh Auditorium at Candler Hospital in Savannah. Bob Staples,

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Next Meeting
April 28, 2012

Director of Safety, Security and Emergency Management has notified his officers on duty that day to provide transportation from the parking lot to the Garden Entrance, which is next to the Auditorium. They have a golf cart and one officer outside the building. They cannot do this for everyone attending the event. Please contact me at JDCprn@aol.com to request the cell phone number needed to request a ride. You need to tell the officer where you are parked and describe your car. It may take a few minutes to get to you.

There are two maps printed in this edition of the newsletter for your convenience. Contact me with any questions that you may have regarding these maps. I worked at Candler 12 years.

I have two suggestions regarding your comfort. First of all, bring a jacket or sweater with you. The room can be cold. Secondly, you may want to bring a cushion with you because the chairs are very hard.

Our program will feature three of our members, Carlos Clas, Marty Foxx and Hugh Munn telling their "polio stories." I am looking forward to hearing all of them.

Your Care Team Leaders will be contacting you regarding your attendance and the number of guests, if any, joining you. The number is needed to order the refreshments being provided.

I look forward to seeing all of you enjoy yourselves.

Janet DiClaudio, President



*"WE'RE STILL HERE!" is the slogan for Post-Polio Health International's "We're Still Here!" campaign, which was inaugurated on October 14-20, 2009. Visit www.Post-Polio.org for more details.

General Meeting Minutes March 24, 2012

President Janet DiClaudio called the meeting to order at 10:43 am and then welcomed Patrina Johnson, Joan Page and Alan Page.

Cheryl Brackin led the Pledge of Allegiance.

Esther Simmons, who works at WTOC TV and is the daughter of Della Simmons, presented 3 CD copies of the "Vaden Extra Mile" televised presentation. We viewed it on her laptop.

The inspiration was given by Terri Dunnermann, who read a story about a House of 1000 mirrors. We reflect to others what we project.

Janet DiClaudio introduced our guest speakers. Suzanne Hertzwig and her husband operate a company called Visiting Angels. They provide living assistance services to

those who want to remain in their home, but need assistance. The group hires Certified Nursing Assistants that are licensed, bonded and insured. It is a private pay company, and they charge an hourly rate that starts at the time they arrive at your home to the time they leave. Some of the services provided include assistance with personal hygiene, light housekeeping, transportation to and from Dr visits to name a few. Suzanne will provide a free consultation. The group was interested in how they may utilize her services for themselves and other family members who need home care assistance versus going to assisted living.

Richard Barid is an Attorney at Law, specializing in Estate Planning/Elder Law/Special Needs. He spoke about the importance of having a will/living trust/power of attorney or other legal documents. This planning allows you to have your affairs in order at the time of serious illness, when you can no longer make decisions for yourself, and at death. Richard discussed the need for long term health care plans. The Veterans Administration has many benefits for veterans that are being missed due to the lack of communication. When hiring contractors for home services, they should be licensed and insured. We the homeowner, do not want to be responsible for incidents that may happen on our property. Richard's practice provides free consultations and recommends needed services. They are licensed.

Business Meeting:

Janet reported that the February meeting minutes were posted in the newsletter. The minutes of the meeting were approved as written.

Janet gave the Treasurer's report in the absence of treasurer Marty Foxx. The report was approved as submitted.

Old Business:

Janet shared Jim Veccia's e-mail relating that we still have \$1000 remaining from the Rotary Grant to spend on mobility assistance. The suggestion was made that we purchase a scooter. Jim will be meeting with Ed Dowaschinski to further discuss use of the remaining funds.

Care Team Leaders Cheryl Brackin, Janet DiClaudio, Wanda Clas, and Lavonne Calandra gave their reports. They identified several members who were having problems at this time and others that are doing well.

Committee Leader Reports:

The Hospitality Committee report from Adrienne Stallworth related that the next meeting will be the 15th Anniversary function at the Marsh Auditorium on April 28th at 10:30 am. Care team leaders will need to get an attendance count when they make their next calls. Cheryl has invited many of our past guest speakers to the function and will report back when they also RSVP. Janet reported that our newsletter will include maps and directions for assistance for getting from the parking lot to the Auditorium. The speakers for the

Anniversary meeting will be Carlos Clas, Marty Foxx and Hugh Munn.

Janet reported for Richard that Charles Orr was given a chair, and Ruth Parham was given a four-wheel scooter from CEPESA. Marty Foxx will be getting a tilt back chair, and Alice Stinnett will also be getting a scooter.

Cheryl reported that she is looking into our using the Georgia Infirmary ADULT DAY CENTER for the June, September and October meetings in 2012. Janet suggested inquiring about the Armstrong Center on Abercorn Extension.

Harvey reported the Rotary District Conference is May 18-20 at the DeSoto Hilton Hotel. We soon will be given more details about how we can participate. Diane is preparing the triptychs and handouts for the event. A sign up sheet will be circulated at the April meeting for members to volunteer to staff the booth.

Adrienne reported that the new directory will be available at the April anniversary meeting. Please send her any new updates and names of new members.

New Business:

Wanda and Carlos have revised the cards and will have them available for members at the anniversary function and at future meetings.

Janet reported that River's Edge management will sponsor a fundraiser for CEPESA on Saturday, August 11, 2012. Several area chefs, including the River's Edge chef, will be cooking for the benefit. More information will be shared in the following months.

The meeting was adjourned at 12:45 pm.

Respectfully submitted,
Michael Dunnermann,
Vice-President/Secretary.

Attendance:

Adrienne Stallworth, Sissy Morel, Ann Chance, Betty Goff, Ross Smith, Penny Smith, Cheryl Brackin, Wanda Clas, Carlos Clas, Esther Simmons, Janet DiClaudio, Michael and Terri Dunnermann, Diane Davis, Barry Turner, Lavonne Calandra, Larry and Charlotte Richter, Harvey Varnadoe, Delores and J.E. McCall, Patrina Johnson, Joan and Alan Page, Marge, Jim Lampke, Tom Shendorff, Suzanne Hertzwig and Richard Barid.

Our April Member Speakers

Our guest speakers for the April 28th meeting will be Carlos Clas, Marty Fox and Hugh Munn. They will be sharing their polio stories with us.



Coastal Empire Polio Survivors Assoc., Inc.

Shining Light on Post-Polio Health

PURPOSE STATEMENT

The purposes of CEPESA 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.*



Early Reminder for May



On May 18-20 the 2012 Rotary District Conference will take place at the DeSoto Hilton Hotel in Savannah's Historic District. **CEPSA members will meet at the DeSoto on Saturday, May 19th, INSTEAD OF MEETING AT CANDLER.** Our new regular meeting place will be announced soon. Everyone is encouraged to sign up at the April meeting (in the Marsh Auditorium) to take shifts hosting the booth that CEPESA will be setting up.

PLEASE NOTE THAT THIS MAY 19th MEETING AT THE DeSOTO REPLACES OUR REGULAR MAY MEETING.

WE WILL NOT MEET AT CANDLER.



*You're Invited to
CEPSA's 15th Birthday Party Celebration.*

When : Saturday, April 28, 2012

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,
Carlos Clas, Marty Foxx and Hugh Munn, 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.

Members, 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.

Coastal Empire Polio Survivors Association, Inc. is a non-profit organization developed in 1997 by three Savannah polio survivors, who were experiencing "The Late Effects of Polio."

CEPSA serves as a vital resource for polio survivors, their families and friends, and the medical community. Our main objective is to offer polio survivors assistance, encouragement, support and Post-Polio Syndrome information.

Our meetings focus on a wide variety of health issues that polio survivors may be facing. Some of our speakers include physicians, occupational and physical therapists, nutritionists, orthotists and experts on Medicare, Social Security, Americans with Disabilities Act and independent living.

We network by sharing information regarding the cause and treatment of Post-Polio Syndrome through our monthly meetings, group discussions and newsletter, THE LIGHTHOUSE.

Our goal is to promote awareness of polio and Post-Polio Syndrome; to help make Savannah and surrounding areas more accessible; and to help the International Post-Polio Task Force motto become a reality:

"Every Child Vaccinated. Every Survivor and Doctor Educated."

S.O.S.

Survivors on Search

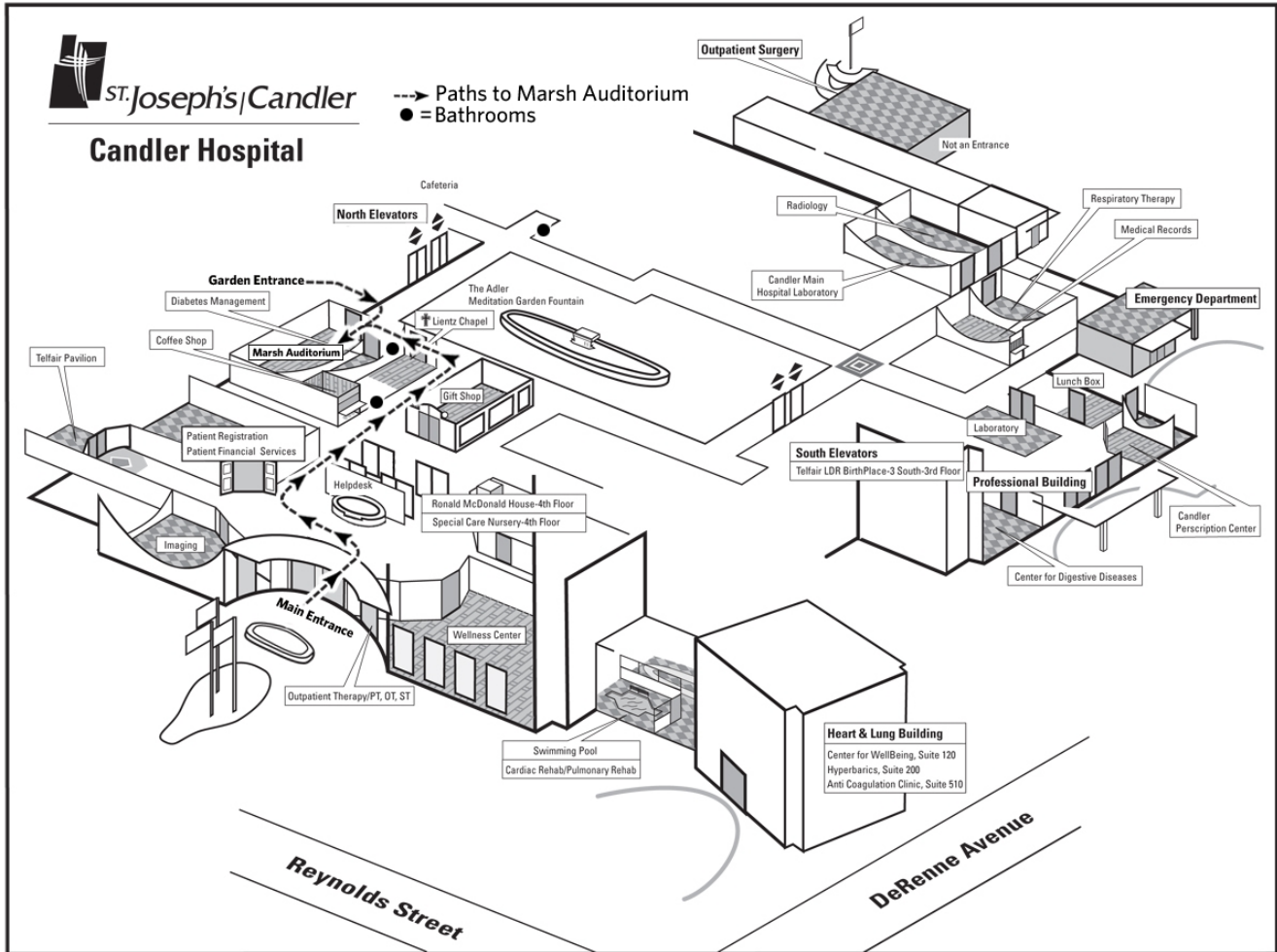
Many polio survivors are experiencing new problems associated with the polio virus that was contracted forty to fifty years ago.

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.

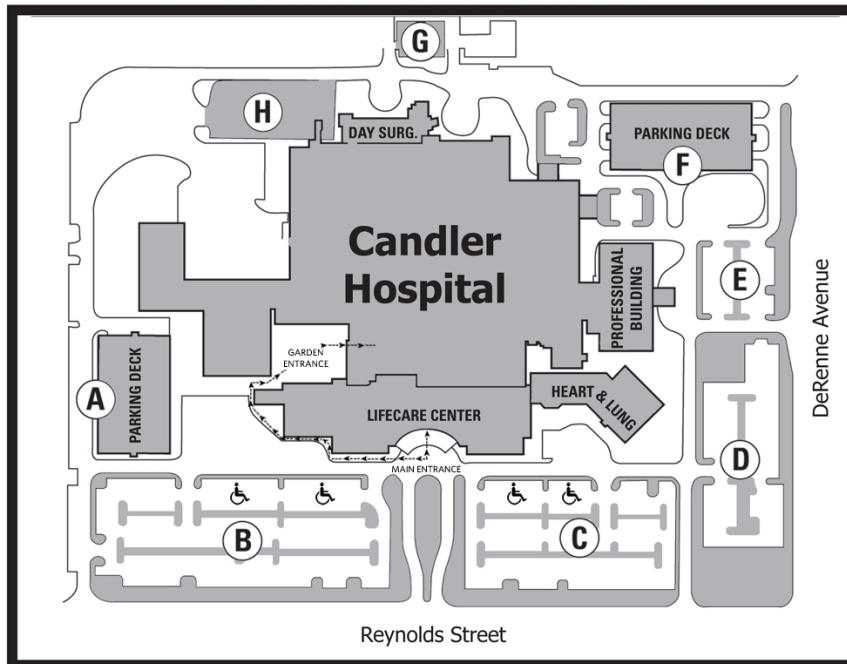
Thank you for your help.

Candler Hospital Main Floor Map & Parking Map



AD20124 (7/10)

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>

The Beginning of the *Coastal Empire Polio Survivors Association* 1997-1999

Our Founders



Shirley Carnell



Lorraine Frew



Cheryl Brackin

Shirley Moorer Carnell, RN, had a dream of starting a post-polio support group in Savannah, Georgia. She worked with Lorraine Frew, RN, at Georgia Regional Hospital. After Lorraine began having some health problems, Shirley noticed her colleague's reduced stamina and began talking about starting a support group for individuals such as themselves. Shirley met Cheryl Brackin, polio survivor and Savannah speech pathologist, at a Warm Springs satellite clinic held by Dr. Paul Peach in Statesboro 1/9/97. She later called Cheryl to share her plans for a group. On 3/18/97 Shirley, Lorraine, Cheryl, and Lila Mae Kicklighter, a long-time advocate for individuals with disabilities, met at the office of Living Independence for Everyone, Inc. (LIFE) on Travis Street. That night the Coastal Empire Polio Survivors Association (CEPSA) was begun. Shirley contacted the Savannah Morning News and asked for an article about post-polio syndrome and our plans to begin a local support group. The lengthy article was accompanied by a striking picture of polio survivor Eileen Renich swimming in a pool for exercise. The date of the initial meeting was announced. On 4/22/97 the GI waiting room of the Candler Professional Building was filled with polio survivors and family members, approximately 35 people. No one was more delighted with the turnout than Shirley. Her dream was on its way.

We began meeting on the 4th Tuesday night of each month at 7:00pm. Within a few months our group relocated to the Candler Heart and Lung Building, 2nd floor, room 2. Lorraine copied numerous articles she and Shirley had collected, so that we could start educating about post-polio syndrome. Cheryl consulted with the presidents of the Charleston, South Carolina and Atlanta post-polio support groups for ideas and suggestions. Shirley had obtained many books on the late effects of polio, and we borrowed and showed a videotape on post-polio syndrome from Charleston. There were several lunchtime meetings with Shirley, Cheryl, Judy Melroy, Charlene Brown, and Tina Settlemire, making further plans for the group.

Program meetings included speakers such as Dr. Ken Griffin (local internist), Dr. Robert Rollings (local cardiologist), Dr. Anne Thompson (RPT and professor in the Armstrong Atlantic State University Physical Therapy Department), Judy DeShea (OTR at Candler Hospital), Dr. Rita DiJokino (Armstrong nutrition professor), Doris Phillips (independent living co-ordinator of LIFE and polio-survivor), Police Officer Famble who discussed personal safety, Gloria Grizzle (the Department of Human Resources) who discussed the Americans with Disabilities Act, and Peter Brodhead of Brighter Day Natural Foods.

The members, spouses, and friends began talking in small groups about post-polio symptoms and problems and sharing solutions. We decided to share our information with the larger community when we scheduled a lecture "Polio: Second Attack" by Dr. Paul Peach, the former director of the Roosevelt Warm Springs Institute for Rehabilitation, on 10/25/97. The session was held at the Marsh Auditorium at Candler, and we had more than 50 registrants. A few nurses and OTs were present, but no local physicians attended. We distributed flyers to the offices of physicians, vocational rehabilitation, LIFE, and other locations. We publicized the event through the local media and had coverage on an evening WTOC news program.

The first slate of officers included Cheryl Brackin, president; Lorraine Frew, vice-president; Beverly Jarvis, secretary; George Frick, treasurer, and Shirley Carnell, founder-mentor. In 1998 the executive committee developed our first bylaws. CEPSA members, a determined though energy-deprived group, held several quite financially successful yard sales. The funds were used for ongoing operation of the association. From the beginning, Shirley wanted our group to become a non-profit organization, which would raise funds to assist polio survivors who had no or inadequate insurance to obtain treatment or needed equipment. We requested information from the IRS office about the requirements for a nonprofit organization. Our very dedicated George Frick began wading through the stacks of forms we needed to understand and complete. We continued to increase our membership and publicize our group. The executive committee decided that we needed to be certain we would remain a viable organization before applying for nonprofit status.

Our database included 80-90 names over the first two years of our existence. We received many telephone calls from interested polio survivors in the early days of the group. Shirley, Lorraine, and Cheryl talked to survivors and mailed information to them. We told them about the post-polio clinics available in Georgia. Many began attending our meetings. Members, including George Frick, Sandra Bath, and Hugh Dunn, shared information by discussing books and articles and also ways for individuals with disabilities to obtain transportation. Lorraine gave an overview of her trip to the Palmyra Polio Clinic developed in Albany, Georgia, by Dr. Peach. CEPSA connected with future medical professionals through the Physical Therapy Department at Armstrong Atlantic State University. A master's level PT student Carrie Scheberies included us in a survey for her post-polio syndrome study in December 1998. The results were published in the *International Journal of Rehabilitation Health*.

Cheryl, the first CEPSA president, joined the LIFE board and served as a liason between the two groups. Pam Hodge, then-director of LIFE, spoke to our members in April 1999. She encouraged us to become active in the disability rights movement in Savannah and across the state and country. CEPSA's involvement in the greater disability community included participating in LIFE's First Freedom March down Bay Street in June 1999 and Disability Awareness Day at Memorial Health University in July 1999. CEPSA members staffed a table and distributed packets to inform the medical community of our existence and efforts to locate polio survivors in Southeast Georgia and the Lowcountry of South Carolina. That mission continues today.

Our Presidents

1997-2012



Cheryl Brackin
1997,1998,1999,2009



Sandra Bath
2000,2001,2008



Beverly Jarvis
2002,2003



Janet DiClaudio
2004,2005,2012



Diane Davis
2006,2007



Jim Veccia
2010,2011

Happy Birthday



April

Fred Davis - 2
Jim O'Kelley - 2
Sissy Morel - 6
Tom Newcomer - 6
Marty Foxx - 8
Stu Robinson - 27
Cornelia Rollins - 27

May

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

Best Wishes



Sally and Ed Luck are moving to Chattanooga. We are very sad to see them go, but we send them off with our best wishes. The CEPSPA family will miss Sally and Ed. May health and happiness always surround them.

Thank You

CEPSA would like to thank Esther Simmons and Sonny Dixon from WTOC, for the DVD copies of the Vaden "Extra Mile Award" commercial, that aired on WTOC TV recently. One of these copies will be included in the CEPSPA History Book. The commercial was shown by Esther at the March meeting. We hope to show it again at the April 28, 2012 CEPSPA birthday party, for all those members who may have missed it.

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

Member Concerns

Eileen Boyle, Lavonne Calandra, Lorraine Frew,
Betty Goff, Richard Graham, Archie Ivey,
Bobby Johnson, Lyn Meeks, Dale Merritt,
Ruth Parham, Dot Parkhurst, Beverley Polin, Penny Smith,
Velma Underwood, Harvey Varnadoe and Jim Veccia.
Please keep these members in your prayers.

Quote of the Month

This month, the quote is really a poem. It was sent in an e-mail from Betty Goff and Lavonne Calandra, on March 26, 2012. We thought it paints a perfect picture of the CEPSPA family. Some members come for a reason, a season or a lifetime, but each leaves a unique impression forever.

PEOPLE COME INTO YOUR LIFE FOR A REASON, A SEASON OR A LIFETIME.

A Reason

When someone is in your life for a REASON, it is usually to meet a need you have expressed. They have come to assist you through a difficulty, to provide you with guidance and support, to aid you physically, emotionally or spiritually. They may seem like a godsend and they are.

They are there for the reason you need them to be. Then, without any wrongdoing on your part or at an inconvenient time, this person will say or do something to bring the relationship to an end. Sometimes they die. Sometimes they walk away. Sometimes they act up and force you to take a stand! What we must realize is that our need has been met, our desire fulfilled, their work is done. The prayer you sent up has been answered and now it is time to move on!

A Season

Some people come into your life for a SEASON, because your turn has come to share, grow or learn. They bring you an experience of peace or make you laugh. They may teach you something you have never done. They usually give you an unbelievable amount of joy. Believe it, it is real. But only for a season.

Lifetime

LIFETIME relationships teach you lifetime lessons, things you must build upon in order to have a solid emotional foundation. Your job is to accept the lesson, love the person and put what you have learned to use in all other relationships and areas of your life.

It is said that love is blind but friendship is clairvoyant.

-Author is Unknown

Notes About Our March Speakers

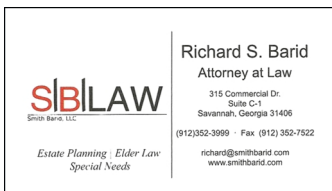


Suzanne Hertzwig is the Director of Visiting Angels, Living Assistance Services in Savannah. They service Savannah, Richmond Hill and surrounding areas 40 miles from Savannah's center. Suzanne can help with a referral for those who are interested who live in South Carolina. The agency is Licensed, Bonded and Insured. They currently have 23 active caregivers ranging in age between 30 through the 50's. If an assigned caregiver cannot be at the client's home when scheduled, Suzanne will step in to provide the client with the necessary service.

Visiting Angels are private pay, but they do work occasionally with the Veterans Administration. If a veteran qualifies, the VA may pay for up to 10 hours per week of care. They charge \$17.95 per hour to start, with a minimum of 4 hours for short term clients. They will charge more for "combative" clients that may be resistant to help. In these types of cases, Suzanne will dispatch her more "seasoned" caregivers. All her caregivers are female at this time.

Their services include up to 24 hour care, assistance in hygiene, meal preparation, medication reminders, light housekeeping and help with errands and shopping.

Please call Suzanne at (912)335-1020 for more information or visit: www.visitingangels.com/savannah.



Richard Barid is a founder and member of the law firm Smith Barid, LLC. He specializes in elder law, estate planning and special needs planning.

He helps families keep their financial affairs in order. This is especially necessary when the person who passes away is the one who maintains the finances. Seven out of ten people pass away without any kind of estate planning, making it very difficult for the surviving spouse and family members.

He can help with specialized programs, like Medicaid and SSI. Richard can help find ways to pay for crisis planning, which are things you can do before you ever have a need.

Richard discussed how he can help a client get the money necessary for care. The Veterans Administration programs were discussed. The Veterans Aid and Attendance is one program that can be looked into if a veteran or spouse need long term care. These funds may even be used for assisted living if the vet or spouse qualify. There are some requirements that Richard can help you with.

You may contact Richard at (912)352-3999 or you can visit: www.smithbarid.com for more information.

www.coastalempirepoliosurvivors.org

Anesthesia WARNING!

I am a *Polio Survivor* with Post-Polio Sequelae (PPS).

PPS unexpected midlife symptoms:

- Heightened Sensitivity to Anesthesia
- Difficulty Breathing
- Difficulty Swallowing
- Cold Intolerance
- Muscle and Joint Pain
- Sleep Disorders
- Overwhelming Fatigue
- Muscle Weakness

Anesthesia WARNING!

I am a *Polio Survivor*.

- I am **EASILY SEDATED** and **DIFFICULT** to WAKE.
- I have **DIFFICULTY BREATHING** with **ANESTHESIA**.
- I have **DIFFICULTY SWALLOWING** with **ANESTHESIA**.
- I am **HYPERSENSITIVE** to **PAIN** and **COLD**.
- I need a **HEATED BLANKET**.
- I may need **INCREASED PAIN MEDICATION POST-OP**.

The card above is CEPSA's version of the **Anesthesia Warning Card** that was created based on a design from the New Jersey Department of Health and Senior Services. We would like to thank Bernadette Marx from the N.J. DOH for allowing us to use their card as a reference for the design of our card.

You should **PRINT THIS CARD IN COLOR** for it to have the best visual impact. If you need an **actual copy** of this card, they will be available at the monthly meetings.

Instructions:

1. Visit the CEPSA website at: www.coastalempirepoliosurvivors.org
2. Click on Newsletter.
3. Under Newsletters 2012, click on April.
4. Print page 9 in color.
5. If you are using heavy stock paper, you can turn the sheet after printing page 9 and print page 10 behind it.
6. If you are using thin, copy paper, print pages 9 and 10 separately. Glue or tape (double-sided tape is best) the pages together, back to back.
7. Trim around the edges.
8. Fold the card in half.
9. Place in wallet. You can show the front or back of the card depending on the style of your wallet.

MEDICAL EMERGENCY CARD

NAME _____ **DOB** / / _____

ADDRESS _____

CITY _____ **STATE** _____ **ZIP** _____

PHONE _____ **CELL** _____ **BLOOD TYPE** _____

EMERGENCY CONTACT

PHYSICIANS:

Name _____ Relationship _____ Phone _____

Name _____ Relationship _____ Phone _____

MEDICAL CONDITIONS: _____

MEDICATIONS: _____

ALLERGIES: _____

OTHER INFO: _____

Anesthesia **WARNING!** I am a **Polio Survivor**. See other side.

Surgery Tips

The Knife is Not So Rough If...

By: Richard L. Bruno, Ph.D.

This is an excerpt from an article by Dr. Richard L. Bruno. Dr. Bruno put this article on the Internet and asked that it be shared with polio survivors. If you have to go under the knife, we suggest that you give a copy of this article to each member of the surgical team and to the nurses on the hospital floor where you will be staying. Discuss the article with your doctor and ask that a copy be put in your medical chart.

PRE-OPERATIVE PREPARATION

This is the most important period, since this is the period when you must establish communication with the surgical team. After a second opinion, meet with the surgeon and the anesthesiologist to discuss in

detail your complete polio and general medical histories and any problems that might arise before and during surgery, in the recovery room and on the nursing floor.

LUNGS:

It is recommended that all polio survivors have pulmonary function studies as part of your preoperative testing. This will help the surgical team evaluate the proper type of anesthesia for you and will help eliminate any unpleasant surprises coming off a respirator at the end of surgery.

PHYSICAL ASSISTANCE:

X-ray and examining tables are built at heights that are convenient for the professional, not the patient. Many polio survivors cannot step on a stool to get on a high table. Polio survivors must ask for help in transferring. Since most polio survivors are not good at asking for help, they need to find a phrase with which they are comfortable that will communicate their needs. If you run into someone that does not want to help or work with you, ask for someone else to help or ask to speak to their supervisor.

GENERAL ANESTHETICS:

Polio survivors are exquisitely sensitive to anesthetic. A little anesthetic goes a long way and lasts a long time due to the damage of the brain stem - called the reticular activating system. Polio survivors have been known to sleep for days after surgery. For polio survivors we use the RULES OF 2 for surgery.

ANESTHETIC RULE OF 2:

Polio survivors need the typical dose of anesthetic divided by 2. This is merely to remind anesthesiologists that polio survivors need much less anesthetic than do other patients. Also, polio survivors can be sensitive to atropine-like drugs used during surgery.

POSITIONING:

One overlooked problem is the positioning of the post-polio patient on the operating table. Muscle atrophy, scoliosis and spinal fusion may make certain positions problematic. It would be advisable for the patient to be awake during positioning on the table to prevent post-op complications.

POST-OPERATIVE CARE

COLD:

Polio survivors are extremely sensitive to cold because they have difficulty regulating their body temperature. No polio survivor should have same-day surgery for any reason except for the most simple procedure that requires a local anesthetic.

POST-ANESTHETIC RULE OF 2:

Polio survivors require 2 times as long to recover from the effects of any anesthetics.

BLOOD AND GUTS:

Polio survivors with muscle atrophy will have a smaller blood volume that would be expected for their weight and height. Therefore bleeding during surgery may be more of a problem. Polio survivors cannot control the size of their blood vessels, since the nerves that make the smooth muscle around veins and capillaries contract were paralyzed by poliovirus. Therefore, polio survivor's blood vessels open under anesthetic and dump the heat of their warm blood into the cold recovery room. Polio survivors must be kept warm.

VOMITING:

Another post-op problem related to brain stem damage is vomiting. Polio survivors are more apt to faint (have vasovagal syncope and even brief asystoles) when they attempt to vomit. It is important that post-op emetic control be discussed with the anesthesiologist and administered before going to the recovery room.

CHOKING:

Polio survivors who are aware of having swallowing problems, and sometimes in those without apparent swallowing difficulty, cannot clear secretions and may choke when they are lying on their backs. Polio survivors secretions need to be monitored in the recovery room and they should be positioned on their side if possible so that secretions can drain.

PAIN:

The single most troublesome problem after surgery is pain control. Under-medication is a serious problem for the post-polio patient since two research studies have shown that polio survivors are twice as sensitive to pain as those who didn't have polio.

RULE OF 2 FOR PAIN:

Polio survivors need 2 times the dose of pain medication for 2 times as long.

RECOVERY:

Polio survivors need more bed rest than most patients, because of autonomic nervous system damage. Polio survivors are the best judges of when they can move, stand and walk safely.

RULE OF 2 FOR RECOVERY:

Polio survivors should stay in bed 2 times longer than other patients.

RULE OF 2 FOR LENGTH OF STAY:

Polio survivors need to stay in the hospital 2 times longer than other patients.

RULE OF 2 FOR WORK:

Polio survivors need 2 times the number of days of rest at home before they return to work or household duties.

RULE OF 2 FOR FEELING BETTER:

Polio survivors need 2 times longer to feel back to normal again.

CONCLUSION:

All of the Rules of 2 are suggestions for polio survivors and the surgical team; they are not a substitute for specific information about the individual patient and communication among all members of the treatment team, including the patient.

Bruno, Dr. Richard. "The Knife Is Not So Rough IF..." Excerpt. [Polio Echo.org](http://www.polioecho.org). Polio Echo, Inc. of Arizona. 24 March 2012 <<http://www.polioecho.org/Surgery.html>>.

CEPSA member Cheryl Brackin distributed this article in its entirety at the March meeting. Copies are still available and can also be found in the "New Members" packets that are available through Harvey Varnadoe. Every polio survivor should have a copy of the FULL ARTICLE available to show to their doctors and dentists. Remember to go through the article with your anesthesiologist before any surgery. This includes oral surgeries.

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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Thank you for your support and encouragement.



Coastal Empire Polio Survivors Assoc., Inc.
23 East 61st Street, Savannah, GA 31405
GA (912) 355-1221 • SC (843) 837-1230
E-mail: CEPSA05@msn.com
www.coastalempirepoliosurvivors.org

Shining Light on Post-Polio Health

CEPSA's next meeting is on
Saturday, April 28, 2012,
10:30 AM
in the Candler Hospital
Main Building,
first floor,
Marsh Auditorium.

