



# THE LIGHTHOUSE

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

January, 2014 Newsletter

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

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## The President's Message...



**H**appy New Year, CEPSA Members and Friends! I hope you and yours had blessed holidays. My beloved family gave me moments of joy that I treasure.

Reflecting on our last 2013 event, we had a wonderful holiday banquet in December. It was good to see so many of you there. Vaneetha Rendall Demski amazed and inspired us as she shared some of her polio story, her life experiences, and her message about gratitude. Kudos to our hospitality chairs Terri Dunnermann and Adrienne Stallworth and their spouses, along with Marty Foxx, Betty Goff, Lavonne Calandra, and Wanda/Carlos Clas, for spearheading another successful event. Thank you to the board members who donated door prizes—Lavonne Calandra, Wanda/Carlos Clas, Diane Davis, Terri/Michael Dunnermann, Lorraine Frew, Betty Goff, Linda/Richard Graham, Adrienne Stallworth, Jim Veccia, and me.

As we move into 2014, my dream is to print more of our polio stories. Time is slipping away. Perhaps some of our polio memories are as well. This year there will be interviews, and stories will be typed for the newsletter. I hope we can publish our stories in a book. We did not choose to be a part of polio history. Still, we should share our experiences with future generations. I continue to meet children and adults who do not know what polio or post-polio syndrome is. Older adults have heard about the epidemics and recall precautions parents enforced. They do not know how the virus is contracted. When someone asks about my condition, I use that as a "teaching moment." I've had poignant moments with my young nephews who ask if my leg will get better. Very gently I tell them "no," but that my brace makes my leg stronger so I can walk.

Your executive board met recently to make plans for 2014. We have two excellent programs already scheduled. Please mark your calendar for January 25 when Alison Walmsley, Occupational Therapist at Chatham Orthopaedics and Sports Medicine, will speak. This outstanding clinician consulted with me about my hand prior to my carpal tunnel surgery. Alison's mother is a polio survivor. This gives her a unique insight into our PPS problems.

CEPSA has a NEW MEETING LOCATION! This month we will be meeting at the Nancy N. and J.C. Lewis Cancer and Research Pavilion on Candler Drive. It is located across Reynolds Street from Candler Hospital. Look for the beautiful building with lots of glass. There is ample parking in front of the Lewis building.

Lastly, I must thank our "underground newsletter editors" Wanda and Carlos Clas for helping me put together this first newsletter. They have been indispensable. I took this job by default. In time perhaps I can "fly solo."

Cheryl Brackin

**Next Meeting**  
Saturday,  
**January 25, 2014**  
10:30 AM  
at Nancy N. and J.C.  
Lewis Cancer and  
Research Pavilion  
Room 203

← 225 Candler Drive, Savannah, GA 31405

## CEPSA 2013 HOLIDAY BANQUET

Our annual holiday banquet held December 7 was a joyful beginning to the season. Members, family, and friends were in great spirits. We had moments for wonderful conversation and hugs before and after the meal and program. Marty and Terri greeted guests warmly as they entered. Lorraine circulated and welcomed attendees. Adrienne and Ed accepted and arranged door prizes. Michael was busily taking pictures for our newsletter and website. Cheryl welcomed everyone, Ed gave the benediction, and lunch was served. The Hilton Garden Inn staff was gracious and helpful as always.

Vaneetha Rendall Demski from Raleigh, North Carolina was our keynote speaker. Her topic "Gratitude Changes Everything" helped us think of our polio experience and other life experiences in a different way. She dispensed gratitude cards to help us practice daily being grateful. This remarkable woman told about contracting polio in India at age three months. She grew up dealing with residuals of polio. Thirty-eight years after getting polio, she developed post-polio syndrome. Vaneetha is living a full life, having obtained a Master of Business Administration degree from Stanford University Graduate School of Business and worked in varied positions. She is raising two lovely daughters. Vaneetha's strong faith was clear as she spoke of her devotion to her church and helping others. Shalini Bennett, Vaneetha's sister, accompanied her to Savannah. It was a pleasure to meet both of these beautiful women. We appreciated their sharing this special day with us. You can visit Vaneetha's website at: [danceintherain.com](http://danceintherain.com).

Lorraine installed the 2014 officers, and Cheryl announced the committee chairs and care team leaders. Michael expressed our appreciation to Marty Foxx for her dedication as CEPSA's treasurer for 13 years. He presented her with a print by Peggy Cone, a local artist. Jim thanked Wanda and Carlos Clas for their two dedicated years as editors of The Lighthouse, our newsletter. He commended their very professional issues and many other contributions, including our updated logo and brochures. Adrienne, Ed, Terri and Lavonne handled the drawing for and dispensing of the door prizes. Lucky winners included Ashley Chance, Diane Davis, Hattie Evensen, Linda Graham, Della Simmons, Penny Smith, Jim Veccia & Jamie Warden. Esther Grace Simmons sang a spirited version of "Chestnuts Roasting on an Open Fire," to close the program.

## In Appreciation

Peggy Cone, award-winning local artist, donated one of her Limited Edition Prints to the Coastal Empire Polio Survivors Association in honor of Marty Foxx for her 13

years of faithful service as Treasurer for the group. Mrs. Cone's lovely Savannah paintings are represented in private collections throughout the United States and Europe. Her artistic talents also are expressed in writing beautiful spiritual poetry. She shares her self-taught gift of playing piano and singing with the residents of various nursing homes in Savannah every week. Mrs. Cone was the guest speaker for CEPSA's 2005 banquet when she did a comedy routine as "Miss Minnie Pearl." She donated a print for the grand prize in the door prize drawing at our 2006 banquet. We appreciate Mrs. Cone's ongoing generous support of our organization.

## A CEPSA Salute

Hats off to Marty Foxx for 13 years of dedication to this organization as Treasurer! We appreciate the countless hours she spent taking care of our financials. Marty has helped CEPSA in many ways, including allowing us to hold two very successful yard sales at her home, maintaining our mailing list and sending out printed newsletters, and thinking of creative, informative programs. She worked with the Clases on the design of our new donation envelope. She has helped to maintain our directory of members. Marty was the leader of the pack when we had "Sharing Our Solutions" at our September 2013 meeting. She showed many devices and told her solutions for making life easier with a disability. This amazing woman could write a book on how to make a home more accessible. Many of you do not know about Marty's quiet help for members, such as taking food following a surgery or paying a power bill for a member who was unable to pay it. She has traveled out of town to check on members or to carry something they needed. We thank you, Marty! Take a bow, and take a well-earned break from CEPSA duties for a while. **(Article Continued on Page 7)**

## Our January Speaker



### Alison Walmsley, OTR/L, CHT, CLCP

Alison Walmsley, Occupational Therapist at Chatham Orthopaedics and Sports Medicine, will present our January program. Her topic is "Making the Most of Your Daily Living." She is the Hand Therapy Supervisor for the department, located on Paulsen Street. Alison has worked in the Savannah community in a number of settings, including St. Joseph's Hospital and Southeastern Orthopedic Center (currently Optim Healthcare). Alison obtained her BS degree from the LSU Medical Center and also has worked in New Orleans. Her professional affiliations include the the American Occupational Therapy Association and the Georgia Occupational Therapy Association.

# Post Polio Syndrome: Recognizing the Unrecognizable

by Henk Snyman, MD

Throughout the 1940s and 1950s, polio emerged as a devastating epidemic that affected thousands in the United States alone. Once the second leading cause of death behind stroke, polio stood as an incurable, viral disease that caused severe pain, breathing difficulties, paralysis, and in many cases, death. The virus crippled children and adults for years until a vaccine finally became widely available in 1955. Although polio has been eradicated in the developed nations of the world, the tides have turned over the past 25 years as polio survivors have begun to experience a range of lingering side effects that significantly affect overall quality of life.

## Causes of Post-Polio Syndrome

The polio virus was originally characterized in three stages, including acute illness, recovery period, and stable disability. In the 1980s, when polio survivors who were diagnosed at a young age began to experience pain, progressive weakness, and fatigue, experts identified a fourth stage of the disease commonly known as post-polio syndrome (PPS). More than half of all polio survivors are now developing the deteriorating side effects of PPS. Considered a progressive neuromuscular decompensation, PPS is surfacing in thousands of Americans, negatively affecting their ability to partake in life's simplest pleasures.

## A Difficult Journey

Navigating through life with PPS is undoubtedly difficult, as mobility is quickly lost and it becomes challenging to live a normal, regular life. The extreme bouts of pain and weakness that accompany the condition can hinder work, familial obligations, and the ability to enjoy hobbies and activities. As a result, many PPS patients become depressed and dormant, ultimately affecting those around them.

Unfortunately, there is no specific cure for post-polio syndrome, and the lack of adequate treatment most certainly leads to feelings of frustration and hopelessness among the afflicted. The lack of a cure is a result of the lack of knowledge surrounding post-polio syndrome. Because PPS demonstrates similar symptoms to other incurable chronic conditions including chronic fatigue syndrome (CFS) and fibromyalgia, physicians are often quick to misdiagnose or even dismiss PPS. Those diagnosed with PPS often

remove themselves from their communities, their work, and even their families. As such, it's particularly important for caregivers to educate themselves on both the physical and emotional side effects of the condition.

## How to Help

A strong support base is critical for those living with post-polio syndrome as it is likely that among other positive effects, the chances the condition will be officially accepted by the medical community will vastly improve if caregivers acknowledge PPS and encourage their loved ones to speak out about it. Fortunately, there are an overwhelming number of PPS communities and support groups that have been established to address the growing concern of post-polio syndrome. These support groups convene regularly to discuss life's challenges associated with PPS and ways in which individuals can move on and rebuild their lives.

The creation of these PPS support groups has garnered the attention of numerous physicians, who have taken a special interest in studying the transformation of the disease and utilizing unique treatments for individuals living with PPS. Over the last few years, specialty physicians, including doctors of osteopathy, acupuncturists, chiropractors and physical therapists, have treated PPS with alternative therapies that have served to create a pathway to a more active, fulfilling life for their patients.

## Life is Possible

Through a recent increase in awareness and attention, post-polio syndrome has started gaining traction and validation within the medical community. And with recent advances in medicine and technology, breakthrough treatments that treat the debilitating side effects of the condition aren't far away.

It takes a strong will to be a caregiver for an individual living with an illness. For caregivers of those with PPS, it is difficult to be the supportive backbone when all others have become skeptics and have dismissed PPS as a serious medical condition. As a result, these providers are encouraged to discuss the condition with their loved ones, and in turn, encourage them to have open communication lines with physicians, medical professionals, and fellow polio survivors.

*Dr. Henk Snyman is the Chief Executive Officer and co-founder of Kingfisher Healthcare, a Belgium-based health care company committed to providing proprietary natural energy devices and accessories. He can be reached at [h.snyman@kfhealth.com](mailto:h.snyman@kfhealth.com).*

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[http://www.caregiver.com/articles/general/post\\_polio\\_syndrome.htm](http://www.caregiver.com/articles/general/post_polio_syndrome.htm)

# Coastal Empire Polio Survivors Association, Inc.

## Annual Holiday Banquet



December 7, 2013

Guest Speaker..... Vaneetha Rendall Demski  
"Gratitude Reframes Everything"



Some days you will be the Light for others,  
and some days you will need some Light from them.  
As long as there is Light, there is hope, and there is a Way.  
- Jennifer Gayle



Photos courtesy of Michael Dunnermann

# Polio Doctors

There is no official certification for a “polio doctor.” The most common use of this informal designation is a physician with knowledge, experience and interest in evaluation and treatment of polio survivors.

Given the most common new disabling medical problems of polio survivors, physicians with expertise in neuromuscular disease management that includes the ability to recognize and treat chronic musculoskeletal pain and respiratory problems are ideal. The specialty background of these physicians is most commonly neurology, physical medicine & rehabilitation, orthopedics and family practice.

Polio survivors do not need to see a “polio doctor” to receive good care. However, if a survivor is experiencing a series of new unexplainable and disabling symptoms and is unable to obtain satisfactory help, then seeking an evaluation by a polio doctor/ post-polio clinic can be very helpful. These physicians most commonly will provide consultation services to your parent’s primary care physician and may provide continuing comprehensive follow-up of post-polio related problems.

Many survivors need a network of medical providers (orthopedist, pulmonologist, orthotist, physiatrist, neurologist, etc.) and may need help with coordination and communication among them. A primary care physician can fill this role, although many polio survivors do this function themselves, because they are sufficiently sophisticated with medical and rehabilitative issues. You as a family member may need to assume this role at certain times.

The best way to frame the issue is this. Are current providers meeting the medical and rehabilitative needs of your loved one? If they are not, then specialist consultations are appropriate. If they need a comprehensive evaluation of medical concerns and functional changes, then seeing a ‘polio doctor’ is invaluable.

If a health professional or facility that provides a comprehensive evaluation is not available, consider the following specialists, in alphabetical order, who may be involved in post-polio care.

## **Behavioral Health Specialist**

Your family member might benefit from seeing a behavioral health specialist. This person might be a psychologist, social worker, licensed counselor, marriage and family therapist, or even a member of the clergy. All behavioral health specialists know about depression, anxiety, and coping with life changes. Some have a special interest in working with elders, people with disabilities, and/or trauma survivors. Rehabilitation psychologists and counselors and gero-psychologists are examples of specialists in the first two areas.

**Geriatricians** have special training in treating the elderly. They focus on improving the health, independence and quality of life of older people. There are 6,400 “geriatric specialist physicians” practicing in the US, and they may be hard to find, but the field of geriatrics includes not only physicians, but physicians’ assistants, registered nurses, nurse practitioners and long-term care nurses.

**Medical social workers (MSWs)** provide psychosocial support to individuals, families, or vulnerable populations so they can cope with chronic, acute, or terminal illnesses. They also advise family caregivers, counsel patients, and help plan for patients’ needs after discharge from hospitals. They may arrange for at-home services, such as meals-on-wheels or home care.

**Neurologists** are physicians who diagnose and treat disorders of the nervous system. They address diseases of the spinal cord, nerves, and muscles that affect the operation of the nervous system. An important aspect of a neurologist’s daily duties is to offer advice to other physicians on how to treat neurological problems.

**Occupational therapists (OT)** enable people to live life to its fullest by helping them promote health and prevent—or live better with—illness, injury or disability. OTs work in hospitals, skilled nursing facilities and other places that treat people who are aging, rehabilitation centers and health and wellness facilities. They assess how a person accomplishes tasks and suggest better ways. Such tasks include getting on and off the toilet, in and out of a car, chair or bed, swallowing, driving, etc.

**Orthopedists** are physicians who specialize in the diagnosis and treatment of disorders of the bones, ligaments, tendons and joints. Setting broken bones, repairing and replacing joints (such as knees and hips), straightening spines and developing prosthetics to replace body parts are specialized skills of this specialty.

**Orthotists (a.k.a. certified orthotist — CO; certified prosthetist and orthotist —CPO; certified prosthetist —CP)** evaluate and treat musculoskeletal disorders by designing and fitting custom-made orthoses or braces. Orthotists work to restore mobility and prevent or limit disability. Be aware that no one specialty “owns” bracing anymore and many specialties get very little training in prescribing braces. However, bracing is always included in the training of physiatrists. Check with the insurance company to see which medical specialty needs to write the prescription.

**Physiatrists, or physical medicine and rehabilitation (PM&R) specialist,** are physicians who are experts at diagnosing and treating pain and at maximizing function lost through injury, illness or disabling conditions through provision of non-surgical treatments, and coordinating a team approach with other physicians and rehabilitation professionals. They treat the whole person and focus on not only treatment, but also on prevention.

**Physical therapists (PTs)** help improve movement and alleviate pain as an alternative to surgery or pain medications. PTs also treat new weakness and loss of mobility for tasks such as walking, climbing stairs and transferring. PTs teach patients how to prevent or manage a health condition, and are uniquely qualified to help design appropriate fitness programs to promote health and wellness. Physical therapists provide care for people in a variety of settings, including hospitals, private practices, outpatient clinics, home health agencies, schools, sports and fitness facilities, work settings and nursing homes.

**Pulmonologists** are physicians who specialize in the diagnosis

and treatment of diseases and disorders of the lungs and respiratory system. Because of the variety of clinical problems encountered, they have knowledge of internal medicine. They are also known as respiratory physicians and respirologists.

**Respiratory therapists (RTs)** work to evaluate, treat, and care for people with breathing disorders. Most respiratory therapists work in hospitals where they perform intensive care, critical care, and neonatal procedures. An increasing number of respiratory therapists work in skilled nursing facilities, physicians' offices, home health agencies, specialized care hospitals, medical equipment supply companies and patients' homes.

**Speech and language pathologists (CCC-SLP)**, sometimes called speech therapists, assess, diagnose, treat, and help to prevent disorders related to speech, language, cognitive-communication, voice, swallowing, and fluency. Speech-language pathologists use special instruments and tests to analyze and diagnose the nature and extent of the problems.

Excerpt from PHI's "Post-Polio Healthcare Considerations for Families and Friends."©

PHI's Post-Polio Directory ([www.post-polio.org](http://www.post-polio.org))

IVUN's Resource Directory for Ventilator-Assisted Living ([www.ventusers.org](http://www.ventusers.org))

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### January

Gigi Veccia - 5  
 Fran Todd - 9  
 Lorraine Frew - 10  
 Penny Smith - 10  
 Delorise Manor - 14  
 Harriett Merritt - 14  
 Linda Graham - 15

### February

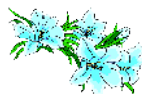
Sharon Underwood - 4  
 Edie Porter - 7  
 Larry Richter - 7  
 Steve Todd - 7  
 Sandra Bath - 16

### Member Concerns

Sandra Bath's sister, Cheryl, Janet DiClaudio,  
 Terri Dunnermann, Archie Ivey &  
 Tom & Eunice Newcomer's daughter, Kim.

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

### Condolences and Concerns



We want to offer our sincere condolences to Tom and Eunice Newcomer on the death of their son Christopher Newcomer in November in Pennsylvania. A memorial service was held here in Savannah at Bull Street Baptist Church on December 2. Adrienne, Lorraine, and Cheryl

were able to attend and offer CEPESA's love and sympathy.

The Newcomers suffered another blow when their daughter Kim was hospitalized in Charleston, West Virginia in mid-December with pulmonary fibrosis of the lungs. She was placed on a ventilator in critical condition. The latest reports have been very good with Kim off the vent, talking and laughing with her family as she recovers. Please remember her and the entire Newcomer family in your thoughts and prayers.

### In Memoriam



Beverly Polin, polio survivor and CEPESA member, died January 10 in South Carolina. She contracted polio in 1941 at age 11 years during an epidemic occurring at Ft. Benning and Columbus, Georgia. She was the only Ft. Benning child who survived that polio epidemic. Although the doctors thought she'd never walk again, Beverly was determined and she did. General Dwight Eisenhower who called her "Blue Eyes" arranged for Beverly to go to Warm Springs for treatment. She met President Roosevelt there. This amazing, determined woman later obtained a nursing degree, then joined the Navy, and obtained a medical technology degree. In 1987 Beverly had to retire from the medical field due to post-polio syndrome. She began wearing braces again, but was able to join her husband in evangelistic work until he died. Beverly found CEPESA several years ago and was able to attend a general meeting and two holiday banquets. We were honored to know this remarkable survivor.

### "A CEPESA Salute" - Continued from Page 2)

Another salute goes to Wanda and Carlos Clas, Newsletter Editors extraordinaire! They produced two outstanding years of our newsletter *THE LIGHTHOUSE*. Members, friends, and professionals in the community constantly were complimenting their issues month after month. Wanda is a gifted writer who summarized many of our excellent programs for the newsletter. The Clases made CEPESA shine with informative newsletters with incredible graphics. Their gifts to CEPESA did not end there. They designed our new logo, letterhead, banner, anesthesia card, and donation envelope. They assisted Harvey Varnadoe in setting up our impressive exhibit at the regional Rotary meeting at the Desoto Hilton Hotel in May 2012. We were blessed when Wanda and Carlos came to CEPESA. We wish them well as they continue plans to sell their home and relocate.

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.



Coastal Empire Polio Survivors Assoc., Inc.  
 23 East 61<sup>st</sup> Street, Savannah, GA 31405  
 GA (912) 355-1221 • SC (843) 837-1230  
 E-mail: CEP SA05@msn.com  
 www.coastalempirepoliosurvivors.org

*Shining Light on Post-Polio Health*

**Next Meeting**  
 Saturday,  
**January 25, 2014**  
 10:30 AM  
 at Nancy N. and J.C. Lewis  
 Cancer and Research Pavilion  
 Room 203  
 225 Candler Drive  
 Savannah, GA



**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, Marty Foxx**  
 23 East 61st Street, Savannah, GA 31405.

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

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

Name of member

***Thank you for your support and encouragement.***