



# The Lighthouse

Coastal Empire Polio Survivors Association, Inc.  
Newsletter September, 2010

Vol. XIII, No. 7

*Shining light on post-polio health*  
[www.coastalempirepoliosurvivors.org](http://www.coastalempirepoliosurvivors.org)

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

TGIO – Thank God It's Over! I'm referring to the brutally hot summer we have endured. I sincerely hope that all of you took proper precautions and carried water with you no matter where you traveled. We are all aware how susceptible we are to cold, but extreme heat is also a no-no for us. The more I read about post-polio from some of our educators, the more I'm amazed that we are surviving as well as we are. Now if we can enjoy a wonderful Fall Season and a very short and not so cold winter!

On July 24th, 28 members and friends got together at Johnny Harris restaurant and had a wonderful luncheon together. We talked and told stories of what we had done and what we had planned for the balance of the summer. The food was good and our conversations lasted for about two and a half hours. On August 28th, 21 of us repeated the luncheon and all had a good time. We had 6 members and friends attending that weren't present at the first luncheon.

We are entering the home stretch of our biggest fundraiser, our Heel to Toe walkathon. I want everyone to push really hard and hopefully we can surpass our fundraising level of last year. Remember, everyone has a certain list of charities they contribute to each year, try to have our project replace one they have on their list. One hundred percent of the money collected goes directly to help eradicate polio (and to CEPSA). CEPSA has obtained a Gold Sponsor (\$1,215) totally through the efforts of Janet DiClaudio and her community, River's Edge, where she lives. She has been fabulous in her pursuit to assist CEPSA in meeting this goal. I cannot say enough about how she has helped us with fundraising. First the dinner, and now this. The Klingensmiths, who manage River's Edge, have been first class in their efforts to help.

I want to be sure everyone knows about returning the money you've collected. If you are planning to attend our monthly September meeting (25th) please bring it with you. If not, please mail it back to me (see below) the week of September 20th. Try not to mail cash; replace it with your personal check. My mailing address is on the form you received in the mail. Bill Gates has upped the ante. He now wants Rotaries across the country to raise two hundred million while he increases his portion to three hundred and fifty million. He feels we are that close to complete eradication. His guru's tell him that is the amount needed to complete the task. So far, the Rotaries have raised a little over one hundred million dollars in almost two years.

Several members have already asked me about obtaining a special rate at the Oceanfront Holiday Inn where the staging area will also be held (their parking lot). I should have that information in about two weeks. I will forward that to all by e-mail. If you do not receive an e-mail, call me and I will give it to you on the phone. (Please see page 3)

There were two "kick-offs" this year--one in Hilton Head at the Mall on August 23rd and a second one in Bluffton at Shults Park on August 24th. Television coverage was supposed to be by WTOG and WSAV, but neither showed. I am really starting to get excited as the time draws near. Please plan on attending the event on October 2nd. Last year we had over forty members and friends attending – I'm sure we can beat that total!!! It's a fun day (ask anyone who attended), and at the end of the walk there will be lots of free food and a load of prizes.

Jim Veccia, *President*, 5 Spartina Point Drive, Hilton Head, SC 29926

## **Minutes for June 26, 2010**

### **General Meeting**

The meeting was called to order by President Jim Veccia at 10:40. After welcoming guests and the Pledge to the Flag, we were inspired by Dan Shehan's poetry reading. Dan also presented the *Accessibility Guide to Savannah's Historic District* which was published by the Savannah-Chatham Council on Disability Issues. Dan thanked Diane Davis for the cover design as well as Harvey Varnadoe and Richard Graham who participated on the committee with him. The 12-page booklet was distributed to all present; 900 copies have been printed with 3500 to be available soon. Congratulations to Dan and his committee for this outstanding publication!

**Melissa Lawrence** from L.I.F.E. gave a brief invitation to the group for the ADA celebration on July 26 at 5:30 at Lou Lou's Chocolate Bar at 72 MLK Blvd. Melissa urged our members to participate in all L.I.F.E. events.

**Dick and Barbara Warden** recently returned from their Honeymoon in the Bahamas. He gave an entertaining report on traveling with a disability and his new leg brace.

Our speaker for the program was **Adrienne Stallworth** on the topic "**Home Record Keeping.**" She distributed a 10-page simple guide for keeping and shredding papers, how to organize a home filing system, Things to Remember, updating the household inventory, making a net worth statement, and protecting yourself from identity theft. There was much discussion about keeping your social security number private and secure. Adrienne also shared with us a 7-page document entitled "**I Love You Letter**" which gives your survivor valuable family business information to use after your death. If you would like copies of these handouts, please contact Adrienne Stallworth at 912-748-8436.

Respectfully submitted, Marty Foxx

#### **CEPSA June Attendance:**

Cheryl Brackin, Archie Ivey, Tony Tedona, Adrienne Stallworth, Tom & Eunice Newcomer, Richard Graham, Raye & Jack Rozek, Ruth Parham, Dick & Barbara Warden, Dan Shehan, Penny & Ross Smith, Harvey Varnadoe, Ed & Sally Luck, Lorraine Frew, Sissy Morel, Melissa Lawrence, and Jim Veccia.

### **HAPPY BIRTHDAY**

#### **September**

Cheryl Brackin – 6	Danny Jenkins –10
Ed Luck –11	Betty Johnson –16
Patrina Johnson –19	Gene Jarvis –22
Richard Hall –24	Dot Parkhurst –27

#### **October**

Billy Ray Washington –3	Eileen Boyle –5
Dan Shehan – 6	Hattie Evensen –7
Skeet Varnadoe –15	Michael Dunnerman –16
Beverly Jarvis –23	Adrienne Stallworth –31

**CELEBRATE!!!!!!!!!!**



#### **MEMBERS CONCERNS**

Adrienne Stallworth    Ed Stallworth  
Hattie Evensen        Harriet Merritt  
Ed and Sally Luck's daughter  
Dot and Bob Pakhurst  
Cheryl Brackin        Lorraine Frew

**CEPSA sends their condolences to Bob and Dot Parkhurst on the death of Bob's mother and Linda and Richard Graham on the death of her aunt.**

#### **CEPSA's Speaker for September**

**Dr. Mark E. Murphy** is a gastroenterologist who along with his six colleagues has the largest gastroenterology practice in Georgia outside of Atlanta: **The Center for Digestive and Liver Health** at 1139 Lexington Avenue in Savannah is recognized as a cutting-edge practice by digestive disease specialists across the State. Dr. Murphy has served on the Board of Directors for Memorial Health University Medical Center, the Crohn's and Colitis Foundation of Georgia and the Georgia Chapter of the American Liver Foundation. He is a graduate of the University of Georgia and the Medical College of Georgia. He did his Internal Medicine residency at the University of North Carolina, Chapel Hill, NC.

We are happy to welcome Dr. Murphy to our September meeting. He will speak on "**Digestive Health Issues for the Polio Survivor.**"

#### **CEPSA's 2010 nominating committee:**

**Janet DiClaudio, Chairperson, Lavonne Calandra, Adrienne Stallworth, Harvey Varnadoe**

## **SPECIAL RATE Heel to Toe**

**Holiday Inn Oceanfront** on Hilton Head is offering a special rate of \$99.00/night. The regular rate is \$119.00/night. Mention Polio Walkathon when calling. The number is 843-785-5126, Speak with Mr. Skip Young.

## **THE “DIVA” OF MOBILITY DEVICES**

*By Kathy Galletly*

*The author had to undergo a revolution in her thinking before she accepted the idea of using a wheelchair*

Mobility devices! You want to talk mobility devices? I am a polio survivor, and I can tell you about mobility devices before the word “technology” existed.

I remember the cumbersome steel braces, the wooden crutches, and those rickety wheelchairs. The only time a polio survivor had a “power” wheelchair is if the neighborhood kids decided to have some fun and pushed you down a hill at warp speed. Oh the thrill of it all; the wind in your hair, the bumps in the sidewalk, your mother screaming at the kids pushing you. Those were the days! After they got you at the bottom of the hill watching them run like the dickens so they wouldn't be in big trouble. Who knows? Maybe that's how the Para-Olympics began.

Some of us with polio were able to leave the mobility devices behind us and go on with our lives. Old rickety wheelchairs, braces, and crutches were something of the past, hidden in the dark corners of our memories. Little did we know that after discarding those mobility devices polio was going to come back and haunt us in the form of post-polio syndrome (PPS), causing fatigue, weakness, and pain in part of our body that were affected by polio, and even in parts we thought that polio didn't affect. When I was first diagnosed with PPS, my first reaction was “I'm not using any mobility device! I don't need a lousy brace; I am not using a cane or crutches. And I'm sure as hell not using a wheelchair! I refused to “give in to mobility devices. So, I kept falling. And as long as I was able to get back up by myself I wasn't going to give in. I was not going to be a disabled kid again, being pushed down the hill by the neighborhood bullies, wondering if the blurs of the trees and houses as I whizzed by in my mobility device would be the last thing I would ever see. In time it became harder to keep up with everyone else. Then I started to need help in getting up. What was even worse, I found myself yelling at my family for helping me. To say I was not a pleasant person to be around was an understatement. By this point I realized I needed help in dealing with the dreaded mechanical enemy. So off I limped, tripped, and fell over my own feet to look for help to accept the devices I needed. It took much therapy, and I offered a lot of diva resistance until I finally came to the conclusion that it wasn't the mobility devices that were the enemy. My thinking was the enemy. I had to accept what I am, that I am disabled, and that was not going to get better and yes, even that a mobility device-power wheelchair-was going to help me live a full, happy and fall-free life. Once I discovered the technical advances of these new mobility devices, and that I was the one who was going to decide what hill I was going down and at what speed, I was off and rolling. When I finally made my way into the world of power chairs, I decided I was going to do it in style; and I was going to be the “Diva of Mobility Devices. My first wheelchair, which I recently had to retire after one-too-many high-speed shopping trips, was Pink Panther pink. I also bought a matching pink crutch and a cane decorated with absolutely lovely little pink roses. When I had to retire my chair, I had a ceremony for it and mourned its loss and moved onto a spiffy new chair. Atlas, the new chariot is not pink, but a lovely cobalt blue. Since I'm just a little older now, the need for speed has left me and I took the high-comfort route. Its seat rises so I can reach my cabinets; its arm swings away so I can get in closer to the table. And when I'm in my chair in the evenings my cats enjoy the newest addition to our lives, and curl up on the cushion, sleeping in high-tech contentment. As I look over at them and hear the sweet sounds of their purring, one thought runs through my mind: Mobility devices – aren't they grand?

Reprinted from *Polio Epic Inc.*, AZ, Dec. 2009/Jan. 2010.

Graphic: <http://www.pridemobility.com/jazzy/600.asp> &  
SECOND TIME AROUND, SEPTEMBER 2010—PUBLICATION OF BOCA AREA POST POLIO GROUP, BOCA RATON, FL

## **Thank You, Richard!**

I want to thank Richard Graham for repairing my scooter. It wasn't working properly for a few months. Thanks to Richard, I enjoyed shopping and running errands yesterday.

For the past few years, Richard has been a big part of CEPESA's “Scooter Project” Jim Veccia started. Richard picks up used scooters and motorized wheelchairs that were donated or purchased by CEPESA (several from S.C.), makes the necessary repairs and delivers them to CEPESA members. He also arranged and oversees CEPESA's storage unit; where we now store the iron lung and scooters he is working on. We all have been touched at one time or another by Richard's kind giving heart. All of us at CEPESA greatly appreciate Richard for giving of himself, his expertise and his time.

Diane Davis

## POTENTIAL OSCAR FOR FILM ABOUT POLIO

Nominated for an Academy Award in the best short documentary category, *The Final Inch* depicts the challenges health workers face while trying to eradicate polio. The film is based in India and on the Afghani-Pakistani border and shows how workers have to persuade some parents of the benefits of immunizing their children. In some predominantly Muslim areas, the communities distrust any vaccinations made in America.

The film's director, Irene Taylor Brodsky, says: "My producer took considerable risks going to Afghanistan to follow polio workers along the Pakistani- Afghani border". She added: "Polio workers risk their lives by just walking outside of their doors every day."

You can see clips of the 38-minute film, *The Final Inch*, and read more about it at: [www.thefinalinch.org](http://www.thefinalinch.org)

Reprinted from *The Bulletin*, UK, March 2009.  
BAPPO Group, FL

Go to that website and click on the trailer. I have to warn you, it may not be for everyone to view.

### **By-Law Amendment to be voted on at the September meeting.**

**Amendment to: *Article II – Purpose***

Amendment addition to read as follows:

H. Promote public awareness of polio, post-polio syndrome, polio immunizations, global polio eradication and local accessibility issues.

Reason given for this Amendment:

CEPSA has been actively involved in all of these areas for the past several years. This bylaw amendment will officially make it a permanent part of CEPSA's purpose.

By-Laws Committee Chair: Jim Veccia Committee: Cheryl Brackin, Lavonne Calandra and Diane Davis

## **CONTRIBUTIONS**

The Coastal Empire Polio Survivors Association is a non-profit corporation which is tax exempt under IRS code 501c(3). We have no paid employees, only volunteers dedicated to helping all polio survivors.

Your financial support is appreciated at any level suggested below:

- \* CEPSA Member - \$15.00 annual voluntary donation
- \* CEPSA Supporter - \$25.00 \$50.00 \$100.00 \$300.00
- \* 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, if so \_\_\_\_\_

Name of member

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