



The Lighthouse

Coastal Empire Polio Survivors Association, Inc.
Newsletter November/December, 2010
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Shining light on post-polio health
www.coastalempirepoliosurvivors.org

The President's Message...

This year has flown by so swiftly it seems like it was only yesterday that I took over the role of president. Being the first male President (following five very talented women) I wanted to be sure that I surrounded myself with the best officers and committee chairpersons possible. I didn't want anything in CEPSPA to move backwards, and I feel that nothing did. I relied heavily on my Vice-President, Diane Davis, whom I bounced ideas off and who helped putting together my agendas for both Board and general meetings. She has truly been my right hand lady! I had complete confidence when Marty Foxx told me she could handle both the Treasurers job and Recording Secretary. She was an excellent caretaker of our money and supplied us with detailed minutes. This had been Marty's eleventh straight year as Treasurer.

My Committee Chairpersons did all I asked of them. Cheryl (publicity) has kept our name and information in the media. Terri and Adrienne (hospitality) did a bang-up job on our party in April, and I'm sure the Banquet will be just as successful. Janet did our correspondence with her great birthday, get well and sympathy cards. Richard has totally taken over control of our scooter project that was introduced a few years ago. He spends so much of his own time picking up and delivering scooters and chairs to needy members, along with doing repairs. Lavonne and Betty have handled our Care Team Leaders and each month reported on our member concerns. Charlotte graciously accepted the role of Newsletter Editor and has delivered wonderful newsy Newsletters each month. Harvey doubles as our New Member and Accessibility Chair. If you find a business that is not accessible, just call Harvey and he will follow up on it. How could I possibly go astray with such caring people to work with as these Chairpersons?

Our Annual Holiday Banquet will have a guest speaker this year. Reverend Justin Epstein will be speaking on his favorite topic: *Forever Young!* He is Pastor of the Unity Church of Hilton Head Island. Rev. Epstein is a dynamic motivational speaker who has given over one hundred and thirty presentations to thousands of people at Lincoln Center's Avery Fisher Hall. He has shared the stage with such notables as Dr. Maya Angelou, Marianne Williamson, Eric Butterworth and Les Brown. He has spoken to groups across the United States and internationally and for companies such as New York's Roosevelt Hospital, Pop Sustainability, and the Hilton Head Chamber of Commerce. He has presented Lifelong Learning programs for The University of South Carolina Beaufort and Hilton Head Island. I'm sure that his talk on living life *forever young*, you will not want to miss.

If you haven't heard from your Care Team Leader and are planning to attend the banquet, please call Lavonne (912-354-2020) or Betty (912-355-8497) to reserve a spot on December 4th.
Jim Veccia, *President*

CEPSA Minutes for October 23rd, 2010

Jim Veccia opened the meeting with a warm welcome to our new members, Marge and Jim Lampke. After Lorraine Frew led us in the Pledge to the Flag, Jim introduced our guest speakers, Bill Byler, owner of **Integrity Medical**, and Dave Byler of **Accessibility Unlimited**. Dave shared his personal family history with us; his struggle to recover from a serious car accident, his special needs granddaughter, and his religious faith led him into the field of assistive remodeling for people with disabilities. Dave's varied work experiences in plumbing, carpentry, and tile prepared him for grant-funded projects to assist people with independent living modifications in their homes. Bathrooms, kitchens, and ramps are often the focus of his work. Some examples of Dave's remodeling include the following:

- Grab bars; Slide-in shower units to replace tubs
- Roll-in showers to use with plastic wheelchairs
- Replacing handheld shower handle with one which will shut-off on the handle
- Door widening; Automatic entry door opening controls
- No permits needed; complete bath redone in 7 days

Dave Byler may be reached at 706-394-1618 or online davebyler@msn.com if anyone wants

further information.

Dave's baby brother, **Bill Byler**, spoke on the Medicare policy changes coming up in January and how they may impact some of us. Competitive bidding changes will put many medical supply companies out of business as Medicare accepts the lowest bid that meets specifications, even if they are out of your area or State. Bill's company, Integrity Medical, provides home medical equipment and supplies as well as services and repairs. He described the process for getting a power chair. It starts with a face-to-face mobility assessment from your doctor who must use a diagnostic code to order a device through Medicare. Bill will conduct a home assessment to determine if existing spaces will accommodate the equipment. Starting in January, power chairs will be given as one month rentals with renewal each month for 13 months. Access to custom-configured chairs may be limited. Often companies quickly secure a bid and then subcontract it out to others. Maintenance of power chairs is paid for by Medicare for 5 years. For more information, Bill may be reached at 912-355-0715. After an informative Question & Answer session, Jim thanked our wonderful speakers for giving us much useful information.

After a short break, Jim called **the business meeting** to order. Janet DiClaudio gave the inspiration using her favorite song lyrics such as "Believe it, Achieve it" and "Accentuate the positive, eliminate the negative." The minutes from the last meeting as printed in the newsletter were approved. Marty Foxx gave the treasurer's report which was approved. **Care Team Reports** began with a warm welcome back to Beverly and Gene Jarvis. The Happy Birthday song was sung honoring Beverly's birthday. Care Team Leaders described a variety of health issues from our members, and improvements were celebrated. Jim announced that Care Team Leaders will be calling for reservations in the next two weeks for our **Annual Banquet on December 4th at 12:00 at the Hilton Garden Inn on Abercorn.**

There were no committee reports. Under **old business**, Jim gave the final report on our **Heel to Toe** fundraiser. The five Rotary clubs and CEPESA raised \$28,000 total; CEPESA contributed \$5000 which was more than a 25% increase over 2009. Thanks to all members who participated in this outstanding effort! The group voted unanimously to commit to next year's joint fundraiser with Rotary.

Under new business, Janet DiClaudio, chair of the Nominating Committee, presented the slate of **officers for 2011:**

President...Jim Veccia Vice-president...Diane Davis
Secretary...Janet DiClaudio Treasurer...Marty Foxx

They were approved by unanimous vote. Janet thanked her committee: Lavonne Calandra, Harvey Varnadoe, and Adrienne Stallworth. Janet also announced that River's Edge will be having a "Pie Baking and Eating Event" on November 12th from 2:00-4:00 as a fundraiser to benefit the World War II Memorial Fund. Information flyers were distributed and participation was encouraged. Dan Shehan made a motion that CEPESA join the Chamber of Commerce. The fee is \$295 and someone would be needed to attend monthly meetings, serve on committees, and attend other special events on our behalf. This connection would promote our public awareness goal. There was much discussion on this issue; some members felt that more information was needed before making a decision. Tom Schendorf amended the motion to delay a decision until after the Executive Board meets November 6th to hear more detailed information from Dan Shehan. The amendment was passed. The meeting was adjourned.

Respectfully submitted, Marty Foxx, Secretary/treasurer

Attendance:

Jim & Gigi Veccia, Diane Davis, Terri & Michael Dunnermann, Dot & Bob Parkhurst, Beverly & Gene Jarvis, Tom Schendorf, Marge & Jim Lampke, Lorraine Frew, Penny Smith, Hattie Evensen, Adrienne Stallworth, Janet DiClaudio, Marty Foxx, Sissy Morel, Harvey Varnadoe, Richard Graham, Dan Shehan, Cheryl Brackin, Joan Page, Betty Goff, Lavonne Calandra, Bill & Dave Byler, Jack & Raye Rozek

HAPPY BIRTHDAY

NOVEMBER

Charlotte Richter – 4
Ann Chance –11
Pixi P. Winters –12
Delores Manor –21
Judy Frick –23
Beverly Polin –25
Velma Underwood –26

DECEMBER

Diane Falgiani –2
Sally Luck –15
Betty Goff –22



Have a Great Day!

MEMBER CONCERNS

Harriett and Dale Merritt
Dot and Bob Parkhurst
Adrienne and Ed Stallworth
Ann Finley Terri Dunnermann
Archie Ivey

Holiday Banquet

If you have recently decided to attend, call Lavonne (912-354-2020) to make reservations. Payments by check would be greatly appreciated. If you have committed to attend but do not come, you will be responsible for the \$18.00 fee that CEPSPA will have to pay for you. Thank you for your understanding in this matter.

PPS FATIGUE HOW IT CAN CHANGE YOUR MIND

Mavis J. Matheson, M.D.

One of the most frustrating late effects of polio for me was the awareness that I could not concentrate and a feeling that I wasn't thinking clearly anymore. For many of us who have compensated for our physical limitations through intellectual pursuits this is a terrifying feeling. Is it not bad enough that our bodies are giving out? Must we undergo the indignity of losing our minds as well? Studies show that in spite of marked impairments of attention, polio survivors are within the high normal or superior range on measures of higher-level cognitive processes and IQ. They also show that if we allow ourselves to become fatigued we do lose our ability to focus our attention and to rapidly process complex information (requiring 23 to 67 percent more time to complete tasks requiring sustained attention and vigilance than did polio survivors with no fatigue or mild fatigue).

Polio survivors experience two kinds of fatigue. One is physical tiredness and decreased endurance. The other and often more distressing kind is "brain fatigue." Brain fatigue describes problems with attention, alertness and thinking. Between 70% and 96% of polio survivors reporting fatigue complained of problems with concentration (96% of polio survivors reporting fatigue complained of problems with concentration (96%), memory (85%), and attention (82%), word finding (80%), staying awake, and thinking clearly (70%). Tests indicate that an impairment of selective attention (related to damage as a result of polio) results in feelings of fatigue and cognitive problems.

The polio virus damages the anterior horn cells of the spinal cord but that is not all it damages. It also damages parts of the brain stem. Findings indicate that polio virus consistently and often severely damaged the brain areas known as the Reticular Activating System. These areas are responsible for activating the part of the brain involved in maintaining voluntary attention, memory, spontaneous interest, initiative and the capacity for effort and work, and for preventing feelings of fatigue. This is the area that keeps us awake and allows us to focus our attention.

Polio survivors report that they are most disabled by the visceral symptoms of fatigue. These are feelings of exhaustion, passivity and an aversion to continued effort that generate an avoidance of both mental and physical activity. Dr. R.L. Bruno suggests the existence of a Fatigue Generator in the brain. His findings suggest that there is a close relationship between impaired attention and fatigue. There would be survival value in a brain mechanism that promotes rest when attention and information processing ability are impaired. An area of the brain (the Basal Ganglia) may generate mental and physical fatigue. When the Reticular Activating System is damaged, the Fatigue Generator takes over and produces problems with focusing attention and with physically moving without significant conscious effort. Damage caused by the polio virus chronically reduces the firing of the nerve cells in the Reticular Activating System. Rest or sleep would increase the firing of the brain activating system nerves, restore activation and once again allow motor behavior.

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The damage would explain why polio survivors have difficulty concentrating after the original infection but why are we developing problems thirty or forty years later? One theory is that the age-related loss of nerve cells combined with an already abnormally small number of nerve cells as a result of the original polio virus infection may impair the brain's activating system enough to produce impaired attention and fatigue as polio survivors reach mid-life.

The first step in treating the disorders of concentration, memory, attention, word finding, staying awake, and thinking clearly is to deal with the fatigue. Energy conservation, work simplification and the proper provision of rest periods throughout the day are the treatments of choice in dealing with post-polio fatigue. Stress management is also critical in the treatment of post-polio fatigue. Dr. Bruno et al are currently studying the use of a medication (a post-synaptic dopamine receptor agonist currently used in the treatment of Parkinson's Disease) in the treatment of post-polio patients who do not respond to conservative treatments. They caution that there is a real danger that treatment with medications will allow Polio survivors to resume their hyperactive Type A lifestyles and further stress polio virus damaged, "metabolically vulnerable" neurons in the brain stem and anterior horn. As with any treatment strategy we must try to find the most effective treatment that will do the least long-term damage while helping us to deal with our current problems. Certainly reducing physical and emotional stresses in our lives and getting adequate rest makes sense for everyone, even polio survivors. The good news is if you can get rested, you will find your ability to concentrate, pay attention, remember words, and stay awake will improve. You may even find that you can enjoy reading and thinking again!

Reprinted from *The Seagull*, NC, October 2009.

Reprinted from BOCA AREA POST POLIO GROUP, BOCA RATON, FL

**CEPSA dues of \$15.00 are due in January. If attending the Banquet you might want to add it to your Banquet check. Otherwise, you can pay at the January meeting or mail it to Marty Foxx
23 East 61st St. Savannah, GA 31405**

CONTRIBUTIONS

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

Your financial support is appreciated at any level suggested below:

- * CEPSA Member - \$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.

