

February, 2012 Newsletter

www.coastalempirepoliosurvivors.org

Vol. XV, No.2

## The President's Message...

One of my responsibilities is to comply with our bylaws. There are eight elements included in Article II: Purpose. We have done a good job, for example, locating polio survivors, educating the survivors and their families about post-polio syndrome, providing financial support for equipment and medical care to survivors, and raising funds to carry out CEPSA's general purposes.

We created a list of six future topics for programs at our January meeting. They are pharmacist, pulmonologist, pain management, home care, depression (including dealing with polio experiences) and an attorney who specializes in elder law. We will try to get them scheduled this year.

We are educating the medical community regarding treating patients with post-polio syndrome. In my opinion, we know more about ourselves than they do. We are the "experts." We have been doing this on an individual basis and it is working.

Another element is to give referrals for medical or emotional assistance. We have created a list of physicians by specialty in our community who are familiar with PPS. Please let us know if you do not have a copy of that document.

We are to counsel as needed or requested. We listen to each other. I have spoken to many of you several times, and my sanity has been preserved.

The last one is to promote social welfare through fellowship and activities such as holiday dinners, conferences, seminars and workshops. We have a banquet and anniversary celebration every year. We sponsored Dr. Holly Wise, a physical therapist from South Carolina, and Dr. Paul Peach, a physiatrist from Warm Springs, GA (now Albany, GA). We have attended conferences in and out of state. Sharing Our Strengths (SOS) is a workshop where we have group discussions on post-polio topics.

Well, it looks like we are doing a good job and need to continue to work toward meeting all of these elements. I am proud of us. See you at Candler.

Janet DiClaudio, President

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## General Meeting Minutes January 28, 2012

President Janet DiClaudio called the meeting to order at 10:40 am and then welcomed Hugh and Linda Munn, Della Simmons and daughter Esther, Marie McManus and Alice Stinnett.

Lorraine Frew lead the Pledge of Allegiance.

The inspiration was given by Terri Dunnermann, who told a story of true love in a moment of aging.

Marty Foxx gave the Treasurer's report which was approved following one correction. There was one noted item explained by Richard Graham. Due to the Rotary's continued success to locate scooters and chairs, a second storage unit has been secured. Members that need devices need to let Richard know of their needs.

#### Old Business:

Heel-to-Toe. Jim Veccia reported that the function has been completed. The Rotary will still consider some function in its place later in the year. We also still have some funds remaining of the \$5000 grant available to secure items prior to the April cut off.

The "Vaden Extra Mile Award" application was submitted and, per Adrienne, we have won a \$500 award. Someone will be needed to receive the check and be on television at that time.

Care Team Leaders Cheryl Brackin, Janet DiClaudio, Wanda Clas, and Jim Veccia gave their reports. They identified several members who were having problems at this time.

#### New Business:

A. THE LIGHTHOUSE: The newsletter was considered well done by our new newsletter co-editors Wanda and Carlos Clas.

B. Meeting Room: The existing meeting room will no longer be available after April 1<sup>st</sup>, and the meetings will be moved to the Marsh Auditorium unless a better location can become available.

C. Emergency Form: Diane Davis explained the need for a list of emergency contacts for members including others than a spouse. The forms would alert us to a contact name and phone numbe if a situation occurred during any of our functions. Forms were distributed and a list will be compiled by our VP/Secretary, Michael Dunnermann and can be used in case an emergency situation developes. The data will be available at all CEPSA meetings/events.

D. Future Programs: Ideas are needed for future programs. Cheryl Brackin reported that today's speaker was unable to attend as he had a family member ill. He plans to reschedule. Some ideas included asking past speakers back due to so many new members. Other suggestions were home care, attorney who specializes in elder law, pain management and accessibility guidelines.

E. Local Rotary: Tom Schendorf reported he has been in conversation with the local Rotary, working with them to consider assistance with lifts, home ramps, shower conversions, emergency services and legal advice. They are interested in having CEPSA provide a display and host a booth at the DeSoto Hilton Hotel on May 18, 19 and 20th during their District Meeting. This will give Rotary a better understanding of Post-Polio Syndrome.

A session of Sharing Our Strengths was then held as members described their good and bad experiences and how to handle ADA concerns while out in public places. The key was that we need to speak up. Managers of businesses want to keep customers coming in and may not understand special needs.

The meeting was adjourned at 12:20 pm.

Respectfully submitted, Michael Dunnermann Vice-President/Secretary.

#### Attendance:

Marty Foxx, Diane Davis, Gigi Veccia, Jim Veccia, Adrienne Stallworth, Ed Stallworth, Lorraine Frew, Sissy Morel, Ann Chance, Tom Schendorf, Sally Luck, Ed Luck, Betty Goff, Ross Smith, Penny Smith, Cheryl Brackin, Nancy Hess, Steve Hess, Lavonne Calandra, Alice Stinnett, Wanda Clas, Carlos Clas, Marie McManus, Della Simmons, Esther Simmons, Linda Munn, Hugh Munn, Richard Graham, Janet DiClaudio, Michael Dunnermann, Terri Dunnermann, Archie Ivey and Lyn Meeks

Voluntary Dues of \$15.00 may be paid to: Marty Foxx 23 East 61<sup>st</sup> Street Savannah, GA 31405 Please try to make your payment this month, either at our next meeting or else by mail. Thank you

## **Thank you** for supporting CEPSA with your generous contributions.

#### 2011 Corporate and Individual Supporters:

In Alphabetical Order:	Betty Pearson		
Auto Shine Car Wash	David Ratchford		
Harold Buttitta	Savannah Orthotics		
Rebecca Cheatham	Sachem Building Supply		
Kenneth Crosswhite	Ron Stephens:		
Ralph Denty	Quick Lock Storage		
Justin Epstein	Sunset Rotary Club of Hilton Head Island		
Jackie Flanagan	Mike Swain		
Judy Frick	Susan Terry		
Janet Goulding	Kenneth Tornvall		
Harckleroad Jewelers	Margaret Tuten		
Hilton Garden Inn	Richard Veccia		
Frances Hodgkins	Steven Veccia		
Integrity Medical	Alan Williams Dr. Holly Wise		
Knox Foundation			
Minuteman Press			
Dr. Mark Murphy	C.D. Zalesky		

#### 2011 Memorial Gifts for Gloria Sullivan:

/

#### Members giving more than dues in 2011:

In Alphabetical Order:	Charlotte Richter
Sandra Bath	Raye Rozek
Eileen Boyle	Kenneth Salter
Deno Caloudas	Tom Schendorf
Janet DiClaudio	Penny Smith
Hattie Evensen	Adrienne Stallworth
Marty Foxx	Barry Turner
Beverly Jarvis	Velma Underwood
Linda Meeks	Dave Vance
Hugh Munn	Harvey Varnadoe
Joan Page	Jim Veccia
Dot Parkhurst	Pixi Winters

## **Our February Guest Speaker**

Our guest speaker for the February 25th meeting will be pharmacist John McKinnon, RPh. Mr. McKinnon couldn't join us in January, but has kindly agreed to speak at our next meeting. His topic will be "Medication Usage in Polio Survivors."



\*\*\*\*\***IMPORTANT**\*\*\*\*\* <u>Please Respond</u> by <u>February 25</u><sup>th</sup>

## Do you need mobility help or have you benefited from our program?

Several years ago, CEPSA instituted a program of obtaining scooters and power chairs and giving them to our members free of charge. We have since obtained a Grant from the Sunset Rotary Club on Hilton Head Island to continue this practice. The Grant also has included car lifts, batteries, repairs and general maintenance. If you are in need of any of these services, please contact Jim Veccia (jimgigivec@aol.com), or Richard Graham (r.graham901@comcast.net) and we will try to accommodate you.

If you have already received help from CEPSA, in any form, and at anytime, recent or previous to our Grant (to show we had instituted the project prior to the Grant), please either e-mail or write me a note <u>detailing</u> the item or services you received and how it has <u>helped you</u> <u>maintain your mobility</u>. I will need to compile this information and present it to the Rotary Club for their records. They must pass it along to their district that is paying for half the Grant. Please try to get this information to me at your earliest convenience or <u>no</u> <u>later than February 25th</u>. We only have a short window until the Grant expires. Thank you.

#### Jim Veccia,

5 Spartina Point Drive, Hilton Head, SC 29926

## You Are Invited

Thank you to everyone who has helped us with THE LIGHTHOUSE and for all your words of praise and encouragement. The Success of THE LIGHTHOUSE depends on the participation of its readers. We would like to *invite you* to participate in future issues. You can submit your thoughts, ideas, suggestions, articles and especially, your polio stories. Contact Carlos Clas or Wanda Clas at: wan519@aol.com or (912)961-4024 We will do our best to publish as many submissions as possible.

### Happy Birthday



February Sharon Underwood - 4 Sandra Bath - 16 Charles Johnson - 22

#### March

Barry Turner - 2 Thelma Tillotson - 4 Tony Tedona - 5 Lavonne Calandra - 7 Glenda Walker - 14 Terri Dunnermann - 18 BJ Vance - 22 Roy Tillotson - 24

#### **Thank Yous**



A Thank You card received from Terri and Michael Dunnerman reads: "Michael & I appreciate the money you gave us toward the price of the scooter lift and the lift and scooter themselves. Thanks again to you all. Sincerely, Terri & Michael."

Dan Shehan wants to thank everyone for their Get Well wishes, cards and prayers while he was recovering. Dan told Richard Graham that he hopes to join us at the February meeting. Let's all wish him continued good health.

#### Quote of the Month

"The most wonderful of all things in life is the discovery of another human being with whom one's relationship has a growing depth, beauty and joy as the years increase. This inner progressiveness of love between two human beings is a most marvelous thing; it cannot be found by looking for it or by passionately wishing for it. It is sort of a divine accident, and the most wonderful of all things in life." *-Sir Hugh Walpole* 

#### **Member Concerns**

Eileen Boyle, Wanda Clas, Lorraine Frew, Delores McCall, JE McCall, Dale Merritt, Harriett Merritt, Eunice Newcomer, Tom Newcomer, Ruth Parham, Dot Parkhurst, Dan Shehan, Barry Turner & Harvey Varnadoe. Please keep these members in your prayers.

#### Condolences



CEPSA would like to offer our condolences to Sally and Ed Luck on the death of Sally's brother, Chandler "Harry" Stevens. He leaves behind his wife of 55 years, Joann (Orcutt) Stevens, his daughters, Emily Stevens-Skahill and Maria Stevens Bollinger, his grandson, Dexter Skahill, his sister, Sally Stevens Luck, as well as a number of nieces and nephews.

Brackin, Cheryl. Portions of an E-mail to Wanda Clas. 1 Feb. 2012.

Our condolences to the family of Elizabeth (Betty) Halbert, our newest member. She joined in December and passed away on Monday, January 30, 2012. There will not be any viewing or services here. She lived all but one and a half years of her life in Texas and everything will take place there.

DiClaudio, Janet. E-mail to Wanda Clas. 2 Feb. 2012.

It is with great sadness that we say goodbye to CEPSA member David F. Vance. Our condolences to David's wife BJ, who is also a member and to their family. David will be missed.

Our condolences and support to the families of CEPSA members who have lost loved ones recently. Eunice and Tom Newcomer's brother (brother-in-law to Tom) and Ruth Parham's brother-in-law will be in our thoughts and prayers.

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

### IN MEMORIAM



Beverly Dean Jarvis 1931-2012

We are rejoicing that Beverly is most likely, as her son and daughter suggest, dancing, jumping, running and singing in heaven. We were saddened to lose her on January 8, 2012 after a courageous and valiant attempt to overcome a stroke from a few months earlier which left her unable to speak. She had already proven that she was a strong person by overcoming polio which struck her as a young adult.

Beverly lived a full, complete, meaningful life. She met Gene Jarvis while she was a church secretary; at their wedding, she WALKED down the aisle using a cane and being supported by her father's arm.

Beverly also worked as a secretary for a major insurance group as well as for the Veterans' Administration. She sang in each of Gene's church choirs. Music wasn't the only artistic endeavor in the Jarvis household; Beverly was a talented and accomplished quilter. Some of her quilts have been featured in *Quilting* magazine, and she actually had her own shows at Hilton Head and Statesboro. Several of her quilts will be shown at the reception after her memorial service. They'll be available to touch and handle; they are works of art, but it wasn't unusual for her children to pile up under one or two on a cold night; the beautiful quilts weren't meant to be shown, but to be used.

Beverly was definitely a strong woman whose faith was what carried her through the challenges in her life. She was also a generous, giving woman, being a caregiver in the last few years of her own mother's life, and then Gene's last few years as well. A close neighbor said recently that Mr. Gene and Ms. Beverly were the greatest neighbors anyone could have and she only wished that Ms. Beverly would have let her do more to help her. However, Beverly's independent attitude was ever present.

When Gene and Beverly moved to Savannah in the 1980s, she became involved with the Coastal Empire Polio Survivors and served as President and worked in many capacities to help make the organization what it is today.

Surviving are her son Paul, his wife Kathy, and their daughter Emory; and her daughter Anne and her husband Dan Roper. There will be a memorial service to celebrate Beverly's life at the Lutheran Church of the Ascension at 2 p.m. on Saturday, February 25<sup>th</sup>. Both Paul and Anne will speak. Immediately following the service will be a reception for her family and friends. The church has an elevator for anyone who wishes to use it.

We will never forget our good friend Beverly and will always be grateful for the impact she had on our lives.

# Cold Intolerance: Why is This a Problem for Many of Us?

By Linda Wheeler Donahue

Cold intolerance is a major problem for many polio survivors. Why do we feel the cold more than people who did not have polio do? This may be a question perplexing you. I would like to share what the polio experts tell us about why we have the difficulty of cold intolerance. Then I would like to explore some practical suggestions to help you obviate this problem. Fortunately, the major polio physicians and researchers are quite consistent in their appraisal of this issue. Let's take a look at what they have to say.

Dr. Julie K. Silver, Director of the International Rehabilitation Center for Polio in Framingham, Massachusetts, explains that polio survivors' sensitivity to cold is due to atrophied muscles that do not contract adequately, and are therefore unable to assist blood vessels in bringing warming blood to the extremities. Dr. Richard R. Owen, Emeritus Medical Director of the Sister Kinney Institute, is one of the first experts to describe "polio feet"; in fact, he coined that phrase. People who had polio often have blue, red, or violet feet. Part of the explanation for our colorful tootsies is that the poliovirus not only attacked our motor neurons, resulting in paralysis of our muscles, but also attacked sympathetic nervous system neurons within the spinal cord. When it did that, we lost our ability to control the blood flow into our veins and arteries. When our veins are unable to contract, they become too open. Blood then "pools" in the feet, giving the skin a bluish tint and causing puffy swelling. Our "polio feet" get colder than the feet of someone who did not have polio, since our sympathetic neurons are damaged. At the time of the original infection, the poliovirus damaged the sympathetic nerves, explains Dr. Lauro S. Halstead, pre-eminent polio author and director of the postpolio program at National Rehabilitation Hospital in Washington, DC. These nerves were part of the autonomic nervous system and their damage caused malfunctioning of the sympathetic nerves. Richard Bruno, Ph.D., clinical psychophysiologist, noticed that the skin on the affected arm of his first polio patient was cold to the touch. This suggested a problem of blood flow to the limb. As Dr. Bruno studied more patients, he discovered the same thing. He deduced that the size of the polio survivor's skin blood vessels could not be

regulated properly because the poliovirus killed off the sympathetic neurons in the spinal cord. These are the ones responsible for making the muscles around blood vessels contract.

People who did not have polio may also experience coldness, but Dr. Silver explains that we polio survivors feel this unpleasant sensation even indoors in a warm room. This sets us apart from others We are often cold even at room temperature because those peripheral nerves that supply the muscles surrounding our blood vessels were damaged when we contracted polio. These small muscles play a major role in warming the extremities.

What can we do to keep warm? Our polio experts all agree on this. The management of cold intolerance is largely symptomatic, that is, all we can do is treat the symptoms. There is no known cure.

How do we treat the symptoms? There are a number of easy lifestyle adjustments you can make. One of the most important things you can do is to stay warm from the moment you wake up in the morning. Your body will be warm and cozy at that time of the day. So hold on to your body heat with warm socks and layers of clothing. Three thin layers will keep you warmer than one thick layer. Go to a camping store and purchase clothing made of polypropylene. Polypropylene is comprised of a thin plastic film woven into a soft fiber and is excellent at insulating your skin from the cold. Outdoorsmen have known of its warming properties for years. It is sold under various brand names such as Thinsulate and Gore-Tex. Skiers and outdoor enthusiasts use a resourceful clothing technique called layering. This is an efficient way to stay warm and comfortable in cold weather by protecting and preserving vour core body temperature. One of the advantages of layering is that you can add or remove clothing to adjust to changing conditions.

Here is how layering works. The first layer is the thermal base layer. The fabrics used for this layer are generally stretch knits, often made of synthetic fibers. They are typically lightweight, machine washable, and fast drying. Special occasions sometimes present a warmth-dilemma for women. I recommend silk as a first layer. Silk is non-bulky with a luxurious feel and has impressive thermal properties. It is light enough to be nearly invisible underneath blouses or slacks, yet insulating enough to provide that extra layer of warmth. With a thin silk layer worn as an undershirt, ladies will look trim even in evening clothes. Fancy dress situations no longer have to mean women are freezing!

The second layer is called the mid layer. This is a

thicker, cozy layer that really locks warmth in next to your body. Fleece, in various thicknesses, is an excellent mid layer insulator. My favorites are Polarfleece 100 and Polarfleece 200. This space age fabric brings comforting warmth, softness, and light-ness. The characteristics of warmth and lightweight are particularly important to polio survivors. We need warmth yet our bodies cannot tolerate dragging around excess weight in the form of heavy clothing. Polarfleece offers a warmth-to-weight dynamic ratio, to traditional fabrics. Its compared tiny springy fibers create multiple air cells to trap warmth inside. This gives

excellent protection from the cold. It does not retain moisture and facilitates evaporation so the fabric remains dry and comfortable. If there is no Polarfleece in your closet, I suggest you head out on a shopping trip. You can shop either in a brick and mortar building or in cyberspace.

The third layer is referred to as the shell layer. This layer must be breathable for the layering system to function. If it is not breathable, condensation will form causing chilling. The top layer, or shell, is often wind-proof and waterproof. It should be loose fitting to allow for movement. Polarfleece 300 as your third layer will keep you warm no matter what Mother Nature delivers.

It is wise to even layer your socks. Sock liners made of polypropylene are superior heat retainers. They are designed to be worn as a base layer under athletic socks. You may want to try battery operated heated socks. I did not have luck with them as they had uncomfortable seams and hot spots, but they may work for you.

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Remember, your entire body must be insulated in order to stay warm, especially in bitterly cold weather. Your neck region is very important. Wear a turtleneck style top to warm that area. In addition, do include a hat, mittens or gloves, warm socks, and a scarf when you venture out of doors.

At the GINI Conference in June of 2000, I purchased a fantastic product from one of the many vendors there. These were heat-activated neck warmer and heat activated booties. You place them in the micro-wave for 3 minutes, then put them on and savor the rejuvenating deep heat for over 20

minutes of warmth. I have since seen these in various home health mail order catalogs.

Many of us PPSers spend most of our time indoors, but we still have trouble staying warm. I suggest that throughout the day you take several breaks from your daily activities. Sit in your favorite chair or recliner with your feet elevated as high as possible. I have an old twin size electric heating blanket draped on my recliner ready to warm me up like nothing else. If you do not need that large a covering, try using a warm heating pad and a cozy lap blanket as you rest and enjoy the feeling of your extremities warming up

to a comfortable temperature. When your muscles are warm, you not only feel better, but you also move and function with more ease and efficiency.

Many of us suffer with the uncomfortable sensation of feeling cold. The foremost polio physicians offer a clear explanation for why this happens. The good news is that we can make lifestyle changes to remediate this troubling postpolio problem.

References: Silver, M.D., Julie K. *Post-Polio Syndrome: A Guide for Polio Survivors and Their Families.* New Haven: Yale University Press, 2001. Halstead, M.D., Lauro S. *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome.* Arlington, VA: ABI Professional Publications, 1998.

Munsat, Theodore L. *Post Polio Syndrome*. City: Butterworth-Heinemann Medical Publishers, 1991. Bruno, Ph.D., Richard L. *The Polio Paradox*. New York: Warner Books, 2002.

**Linda Wheeler Donahue**, Professor Emeritus of Humanities, is a polio survivor, a disability activist, writer, and speaker. She is President of The Polio Outreach of Connecticut and is a frequent presenter at conferences, focusing on the social/emotional complexities of disability. Linda welcomes feedback at LinOnnLine@aol.com.

Reprinted from Connections, Spring 2011– Publication of First Coast Post Polio Support Group, Boca Raton, FL

## FALLING AGAIN AND AGAIN

At our regular Central Virginia Post Polio Support Group Meeting on March 7, 2009, we had a general discussion among the approximately twenty members present. The weather was unseasonably warm, but six days earlier we had a 6 to 8 inch snow storm and many of us recounted some difficult times we have encountered with snow and ice. Some of our members lost electric power and this circumstance can lead to increased feelings of anxiety. We also talked about our dependence on others in stressful situations.



Some of our members live alone and have increased vulnerability as a result. Among the members at this meeting twice as many of the polio survivors had sustained fractured bones from falls compared to the able bodied members present. In 1996 I wrote an article entitled "Falling." Seven years later in 2003 I wrote another similar article entitled "Falling Again." This article is a composite of both articles with some updates.

Some of us have vivid and unforgettable memories of falls we had in our youth because of the residual effects of polio, and others have equally memorable accounts of falls that we have had because of the effects of Post Polio Syndrome (PPS). An additional problem now is that we are older and probably do not fall as gracefully as we once did. Also, the risk is greater for injury because of weaker muscles, softer bones, and the same factors of aging that everyone experiences. Falling is no fun, but dealing with its reality may build character.

Some years ago, I made a list of all the falls that I could remember. Of course, the bad or spectacular falls are more easily recalled. My list came to about twenty-eight falls. The first occurred in 1950 in the halls of the Medical College of Virginia Hospital when I first learned to walk with two long leg braces and two crutches. Somehow, I lost my balance and fell backward like a small tree that had been cut at the base. My head hit the marble floor and I almost lost consciousness. However, I was picked up, and walked back to my bed. My most recent fall occurred in 2006 when I accidentally pushed against the forward switch on my power wheelchair while I was transferring from my bed to the chair. I was standing and the moving chair knocked me over. Fortunately with the help of my wife Brenda and one of my summoned patients nearby I was pulled up on the bed and could get back up. I was fortunate in that I did not sustain any injury. Some of my falls have produced considerable pain, swollen joints, large bruises, and anxiety. Pain is no fun, but dealing with it may build character.

For many of us the experience of terror occurs during that second or less when we realize that we have lost our balance and recovery of balance is impossible. To put it another way: "I have lost control and I am going to hit something for sure." A lot does depend on what we hit, and what part of our body hits first. I have fallen on marble, slate, wood, rugs, grass, dirt, concrete, snow, ice, and stairs. The part of the body that usually hits first is any one of the four extremities (elbows, hands, knees, hips) or unfortunately the head or chin. During that split second of falling weightlessness, our autonomic nervous system kicks into the fright or flight mode. We cannot flee, thus, we have more of the fright mode. By the time we land, our hearts are racing, the respiratory rate is increased, and we are probably breaking into a sweat. If we did not sustain a serious injury, this extra adrenalin helps us get over the immediate effects of the fall. Of course, later, we are quite sore and fatigued, but grateful that nothing really bad happened. Fear is no fun, but dealing with it may build character.

Falls can result in serious injury or life threatening situations. About twenty years ago

when I was leaving my office rather late one night, I fell on ice about midway between my office and my car. It was very cold. Because of the slippery ground, I was unable to get any traction, and could not get up. I was totally alone. I decided to crawl to my car. With my last source of energy, I was able to pull myself into the car, and get it started, and eventually I warmed up. This experience taught me about vulnerability, and having better options for help. Even with precautions, bad things can happen.

I am confident that each of you has experienced the reality, pain, fear and adversity of falling. There are many amazing stories that could be shared by all of our membership. Depending on each person's degree of physical handicap, our falls may have been more frequent and more dangerous. Decades ago, whatever the severity of the handicap, all of us were encouraged and motivated to get back on our feet, no matter what it may take. If we did not get back on our feet, then the world of the polio years was inaccessible. That world included schools, stores, houses of worship, some parks and many homes. I know that my experience included many falls, some more memorable than others. Like many PPSers, I have slowed down, am more cautious, and take all precautions to prevent falling. I began using a scooter on a part time basis in 1991. By 1996 I began using my scooter almost all of the time and in 2003 I acquired a power wheelchair. I use the same power wheelchair today. Also in 2002, I became totally ventilator dependent to prevent respiratory failure. I carry a portable ventilator on my wheelchair. With these adaptations I have conserved my energy and reduced the risk of falling. No matter the precautions, falling and other types of accidents are a reality to all PPSers. We can always fall again.

Often I feel that my vulnerability is almost overwhelming or too frightening to think about, but I cannot escape reality. Sometimes I think of my faith as a source of strength. I think of the faith of the Apostle Paul and how he dealt with adversity. Just before his shipwreck described in Acts 27, Paul states in verses 22-24: "But now I beg you, take courage! Not one of you will lose your life; only the ship will be lost. For last night an angel of the God to whom I belong and whom I worship came to me and said, 'Don't be afraid, Paul!'" While lying on the ground, concrete or whatever it may be I have never seen or heard an angel of the Lord, but I have felt the presence of loving souls, in essence saying, "Don't be afraid, Henry."

Many falls I will never forget. Turning over in a scooter or wheelchair, falling down a flight of steps, falling in the bathroom or shower, and falling in the comfort of your home can potentially be fatal. A head injury could lead to death.

Fractures of major bones can lead to necessary surgery. The risk of surgery in polio-damaged limbs can increase the risk for clots. We are all older and do not recover as ably as in the past. The stress and shock of a fall can have an adverse effect on our cardiopulmonary-vascular systems. Many PPSers take medication for hypertension and diuretics to reduce dependent edema. A sudden added stress on our bodies can increase the risk for stroke, heart attack, and clots. We could live in a vacuum and still there is no absolute safeguard against falling and other accidents.

Pain and fear are the expected results of a fall, even when no real damage is done. How do we go about coping with the possibility of falling and the resultant pain and fear? Do we simply deny the reality of this possibility? Do we allow fear to cause an obsessive concern about falling, resulting in even greater life restrictions? I think we have to accept the risks inherent in living with PPS just as we did with polio. I think we should adhere to practical and doable precautions. We probably should avoid being alone as much as possible. If we are alone we should have a cell phone on our person or a phone attached to our wheelchair or scooter. I think it is also wise to have a flashlight within close reach whenever one goes out at night or in case a power failure occurs at home. I would recommend that Post-Polio Support Groups discuss the risks of falling as a program topic at a meeting. Many experiences can be shared and good ideas can result from such a discussion. I am confident that each of you has experienced the reality, pain, fear, and adversity of falling. There are many amazing stories that could be shared by all.

Originally from Polio Deja View, Va, Apr/May 2009. Reprinted from Second Time Around, April 2010-Publication of Boca Area Post-Polio Group, Boca Raton, FL

# Heart Health: What You Need to Know



Although heart disease is sometimes thought of as a "man's disease, it is the leasing cause of death for both women and men in the United States, with women comprising 51 percent of the total heart disease deaths.

While heart disease is the number one killer of women, only 13 percent of women in a 2003 survey by the Centers for Disease Control were aware that this is their greatest health problem. Here, the term "heart disease" refers to the broadest category of "diseases of the heart," which includes acute rheumatic fever, chronic rheumatic heart disease, hypertensive heart disease, coronary heart disease, pulmonary heart disease, congestive heart failure, and any other heart condition or disease.

Studies among people with heart disease have shown that lowering high blood cholesterol and high blood pressure can reduce the risk of dying of heart disease, having a nonfatal heart attack, and needing bypass surgery or angioplasty.

Studies among people without heart disease have shown that lowering high blood cholesterol and high blood pressure can reduce the risk of developing heart disease.

#### Facts About Women and Heart Disease

Heart disease is often perceived as an "older woman's disease," and it is the leading cause of death among women age 65 and older. However, heart disease is the third leading cause of death among women age 25-44 years of age and the second leading cause of death among women aged 45-64 years. Additionally, in 2002, death rates for heart disease were higher among black women than among white women.

There is a range of risk for heart disease depending on family and personal health history and the treatment recommendations from a physician will depend on a woman's level of risk. Regardless of the risk level, these life style modifications are recommended for all women:

- Cigarette smoking cessation
- 30 minutes physical activity most days
- Heart healthy diet with weight maintenance / reduction.
- Evaluation and treatment of depression

#### Facts About Heart Failure

■ Heart failure is a condition where the heart cannot pump enough blood and oxygen to meet the needs of other body organs. Heart failure does not mean that the heart has stopped, but that it cannot pump blood the way that it should.

■ Heart failure is a serious condition. There is no cure for heart failure at this time. Once diagnosed, medicines are needed for the rest of the person's life.

■ The risk of death within five years of being diagnosed with heart failure is more than 50 percent. About 80 percent of men and 70 percent of women with heart failure under the age of 65 die within eight years.

■ People with heart failure are at increased risk for sudden cardiac death. Source: Center for Disease Control

# Women Experience Different Symptoms from Men

Heart attack symptoms in women are often more subtle than those experienced by men. Women are more likely to experience the following symptoms during heart attacks:

- Fatigue
- Anxiety
- Sleep disturbance
- Stomach complaints

Unfortunately, these symptoms are not generally associated with an AMI (acute myocardial infarction). Even members of the medical profession sometimes fail to link these symptoms with heart problems. It is not unusual for a woman's heart attack to be dismissed as anxiety.

Although considered a classic heart attack symptom, chest pain is not commonly experienced by women. Results from a survey of 515 women published in the American Heart Association's journal Circulation, revealed some interesting statistics: more than 70 percent of women experienced no chest pain prior to the attack, and as many as 43 percent of women reported no chest pain symptoms during the attack.

Further, women who do experience chest pain may describe the pain as "sharp," rather than "crushing." This description does not match the popular (and traditional medical) perception of heart attack symptoms, and may be misdiagnosed.

Additionally, in the days before the attack, 95 percent of women surveyed reported unusual symptoms; the most common being fatigue, anxiety, and sleep disturbances. This list presents some of the common symptoms experienced by women both prior to and during a heart attack. These symptoms are important to consider in addition to chest pain, since in some women they may be the only symptoms present.

#### Symptoms Before an Attack

Fatigue (71 percent) Sleep disturbances (48 percent) Shortness of breath (42 percent) Indigestion (39 percent) Anxiety (35 percent) Symptoms During an Attack Shortness of breath (58 percent) Weakness (55 percent) Fatigue (43 percent) "Cold sweat" (39 percent) Dizziness (39 percent) Source: NCERx

Reprinted from Elder Update, May-June 2006, Health and Wellness

## Old Age, I Decided, is a Gift

I am now, probably for the first time in my life, the person I have always wanted to be, Oh, not my body! I sometime despair over my body, the wrinkles, the baggy eyes and the sagging butt. And often I am taken aback by that older person that lives in my mirror (who looks like my mother!), but I don't agonize over those things for long.

I would never trade my amazing friends, my wonderful life or my loving family for less grey hair or a flatter belly. As I've aged, I've become more kind to myself and less critical of myself. I've become my own friend. I don't chide myself for eating that extra cookie, or for not making my bed or for buying that silly cement gecko that I didn't need, but looks so avant-garde on my patio. I am entitled to a treat, to be messy, to be extravagant. I have seen too many dear friends leave this world too soon; before they understood the great freedom that comes with aging.

Whose business is it if I choose to read or play on the computer until 4 a.m. and sleep until noon?

I will dance with myself to those wonderful tunes of the 50's and if I, at the same time, wish to weep over a lost love... I will.

I will walk the beach in a swim suit that is stretched over a bulging body and will dive into the waves with abandon if I choose to, despite the pitying glances from the jet set. They, too, will get old.

I know I am sometimes forgetful; but then again, some of life is just as well forgotten. I eventually remember the important things.

Sure, over the year my heart has been broken. How can your heart not break when you lose a loved one or when a child suffers or when a beloved pet passes on. But broken hearts are what give us strength and understanding and compassion. A heart never broken is pristine and sterile and will never know the job of being imperfect.

I am so blessed to have lived long enough to have my hair turn gray and to have my youthful laughs be forever etched into deep grooves on my face. So many have never laughed and so many have died before their hair could turn silver.

As you get older, it is easier to be positive. You care less about what other people think. I don't question myself anymore. I've even earned the right to be wrong.

So, to answer the question, I like being old. It has set me free. I like the person I have become. I am not going to live forever, but while I am still here, I will not waste time lamenting what could have been or worrying about what will be. AND I shall eat dessert every single day!

Reprinted from the Florida East Coast Post-Polio Support Group Newsletter, Jan-Feb. 2007- Ormond Beach, FL

## **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
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23 East 61st Street, Savannah, GA 31405.

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Thank you for your support an	d encouragement.		

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#### Shining Light on Post-Polio Health

CEPSA's next meeting is on Saturday, February 25, 2012, 10:30 AM in the Candler Hospital Heart & Lung Building, second floor, conference room.