



# THE LIGHTHOUSE

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

March, 2013 Newsletter

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

Vol. XVI, No. 3



## The President's Message...

**H**appy St. Patrick's Day! Happy Springtime! We are leaving our strange winter with its wet Christmas, icy windshields, 80-degree days, deluge of rain, snowy owl on Tybee, and azaleas and Japanese magnolias blooming in January. As March begins, the promise of spring is in the air. For many of us spring is our favorite season. CEPSA members especially look forward to the annual celebration of our group's anniversary. Please mark April 27 on your calendars, and join us as we turn "sweet 16."

Our February program on crime and safety was a winner. Corporal John Simmons, Crime Prevention Officer of the Savannah-Chatham Metro Police Department, made an excellent presentation. He truly is one of "Savannah's finest." As individuals with disabilities, we need to follow his advice to maintain our safety at home and in the community.

CEPSA has had a splendid beginning in 2013. We've had excellent attendance, programs, and interaction. Another major project has been completed with the shower modification at the home of Lorraine Frew. Our group successfully collaborated with the Skidaway Rotary to help a polio survivor maintain her independence and safety in her home. Thank you, Skidaway Rotary and Belfor, for all you did! Thank you, Tom Schendorf and Harvey Varnadoe, for being our liaisons on this project! Congratulations and happy showering, Lorraine!

Cheryl Brackin, President



**Spring Begins on March 20, 2013 at 7:02 AM.**



## St. Patrick and the First St. Patrick's Day Parade

Saint Patrick, who lived during the fifth century, is the patron saint and national apostle of Ireland. Born in Roman Britain, he was kidnapped and brought to Ireland as a slave at the age of 16. He later escaped, but returned to Ireland and was credited with bringing Christianity to its people. In the centuries following Patrick's death (believed to have been on March 17, 461), the mythology surrounding his life became ever more ingrained in the Irish culture: Perhaps the most well known legend is that he explained the Holy Trinity (Father, Son and Holy Spirit) using the three leaves of a native Irish clover, the shamrock.

Since around the ninth or 10th century, people in Ireland have been observing the Roman Catholic feast day of [St. Patrick](#) on March 17. Interestingly, however, the first parade held to honor St. Patrick's Day took place not in Ireland but in the [United States](#). On March 17, 1762, Irish soldiers serving in the English military marched through [New York City](#). Along with their music, the parade helped the soldiers reconnect with their Irish roots, as well as with fellow Irishmen serving in the English army.

St. Patrick's Day. (2013). The History Channel website. Retrieved 8:25, February 26, 2013, from <http://www.history.com/topics/st-patricks-day>.

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**Next Meeting**  
Saturday,  
**March 23, 2013**  
10:30 AM

Coastal Empire Polio Survivors Association, Inc.  
**General Meeting Minutes for  
February 23, 2013**  
Location: Exchange Restaurant

President Cheryl Brackin called the meeting to order at 10:30am and then welcomed everyone. She requested that those wishing to stay over for lunch mark a menu, indicating their orders. The purpose was to expedite service following the meeting.

Lorraine Frew led the Pledge of Allegiance.

The inspiration was given by Terri Dunnermann, who read an untitled story about "a mousetrap in the house." It reminded us to be aware of others when they are in time of need.

**PROGRAM:**

"Crime, Safety and You" was presented by Corporal John Simmons of the Savannah-Chatham Metro Police Department. The topics covered indicated ways for us to stay safe not only when out and about town, but in our homes as well. (See pages 4 & 5 for Program notes.)

**BUSINESS MEETING:**

**Approval of Minutes:** Minutes from the January meeting posted in our newsletter were approved, following correction of a spelling error.

**Financial Report:** The treasurer's report was given by Marty Foxx and approved as presented. Marty noted that we have reserved the banquet room at the Hilton Garden Inn for our holiday luncheon on December 7.

**Care Team Reports:** The care team leaders reported no significant member concerns. Marty visited Janet DiClaudio in Statesboro and said that she is making good progress in her recovery.

**Old Business:** Lorraine reported that the Skidaway Rotary project for the bathroom modification at her home is almost complete. The Belfor group has done an excellent job. Due to unforeseen issues, completion has taken longer than projected.

Cheryl reported that we continue to work towards getting free postage for mailing of our newsletters.

**New Business:** Sandra reported that the 11th Polio Health International Conference will be held in St. Louis in 2014.

**Announcements:** Cheryl reminded everyone that our care team leaders will call in April to talk to you about the 16th Anniversary celebration to be held on April 27th at the Marsh Auditorium. Please plan to attend.

The meeting was adjourned at 12:34 pm.

Respectfully submitted,  
Michael Dunnermann, Vice-President/Secretary

**Attendance:** Cheryl Brackin, Wanda & Carlos Clas, Diane Davis, Esther Simmons, Della Simmons, Michael & Terri Dunnermann, Delores McCall, Dorothy Lewis, Tom Schendorf, Marty Foxx, Ross & Penny Smith, Lavonne Calandra, Betty Goff, Sissy Morel, Dan Shehan, Lorraine Frew, Barry Turner, Sandra Bath, Charlotte & Larry Richter, Hattie Evensen, Robert Allen, Adrienne Stallworth, Jim and Gigi Veccia, Richard Warden .

**See You There!**

CEPSA's **meeting place** is at:  
**The Exchange (Restaurant) on Waters,**  
6710 Waters Avenue  
Savannah, GA 31406

\*\*\*PLEASE ENTER THE MEETING ROOM THROUGH  
THE RIGHT SIDE OF THE BUILDING.\*\*\*

**Our March Program**

Our March Program is one of our favorites, Sharing Our Strengths or S.O.S. It is a great opportunity for our members to come together and share their know-how. Someone may have information that can be helpful to someone else in the group, and this is the perfect chance to spread the knowledge. S.O.S.

Suggestions for future meetings are always welcome. Please let Cheryl Brackin know about your ideas for future speakers.



\*\*\*EARLY REMINDER\*\*\*

**Tax Filing Deadline is  
Monday April 15, 2013.**

**DID YOU KNOW...**

**your voluntary dues help us cover the cost  
of producing this newsletter?**

**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.**



## to our Generous Supporters in 2012:

In Alphabetical Order:

Alan Williams of Williams Insurance Company  
 Batteries Plus  
 Dan Vaden Extra Mile Award Program  
 Hilton Garden Inn  
 The Knox Foundation  
 Living Independence for Everyone  
 Minuteman Press  
 Pine Haven Baptist Church of Brunswick, GA  
 Ron Stephens at Quick Lock Storage  
 Rosalee Nguyen Brackin Floral Designs  
 Rotary Sunset of Hilton Head  
 The Strickland Family at Strickland's Funeral Home

## Memorial Gifts, Honorary Gifts, and Donations from members giving more than dues in 2012:

In Alphabetical Order:

Sandra Bath	Gordon Sherland
Cheryl Brackin	Malcolm & Carleen Smith
Rebecca Cheatham	Mr. & Mrs. Jack Snyder, Sr.
Joan & Julius Deen	Sowers Sunday School Class,
Janet DiClaudio	First Baptist Church,
Lloyd & Barbara Douglas	Springfield, GA
Hattie Evensen	Dyrke Spiker
Mr. & Mrs. Orland Finch	Ed & Adrienne Stallworth
Marty Foxx	Franklin & Phyllis Stevens
Judy Frick	Michael H. Swain
Betty & Gene Goff	Sheila Tillman
Jay Grinney	Fran Todd
Frances Hodgkins	Jean Toole
Edith & Robert Mingledorff	Kenneth Tornvall
Delores McCall	Velma Underwood
Lisa Ostrowski	Barbara J. Vance
William Pierce	Harvey Varnadoe
Dennis Price	Jim & Gigi Veccia
Charlotte & Larry Richter	Richard Warden
Kenneth Salter	Mr. & Mrs. R.E. Whiddon
Tom Schendorf	Robbie White
Nancy Sheffield	



## Care Team Phone Calls

Your Care Team Leaders have been doing a great job calling members every month. They call to make sure you are okay, to see if you need anything, to update your information or just to listen and offer a friendly hello!

NOW, THEY NEED YOUR HELP.

Please, get back to them when they call or if they leave a message. If you prefer not to have someone call or if you tell your Care Team Leader to leave a message, they will be happy to do so.

This month when they make their monthly call, they will also ask if you will be attending CEPESA's 16<sup>th</sup> anniversary party at Candler Hospital's Marsh Auditorium on April 27, 2013.

They really need a correct head count so that our Hospitality Team can order enough food and drinks for everyone. They are "counting" on you to help them!

THEY REALLY NEED YOUR CALL-BACK,  
ESPECIALLY NOW.

## Wheelchairs and Scooters Are Available

Jim Veccia would like to remind everyone that CEPESA still has wheelchairs and scooters available for anyone who needs one. Please don't hesitate to call Jim at (843) 837-1230 or Richard Graham at (912) 728-3393 to let them know what you need. Having a working wheelchair or scooter can give you more mobility and independence. These items are **FREE** to CEPESA members.

## Volunteer Needed

We need a volunteer to videotape our 16<sup>th</sup> anniversary speakers at the Marsh Auditorium on April 27<sup>th</sup>, 2013. You will be videotaping our three speakers for this year. Our speakers will be Hattie Evensen, Harriett Merritt and Barry Turner. This video will be archived along with other CEPESA memorabilia by our History Chair, Diane Davis.

We really need your help. If you would like to volunteer, please let Cheryl Brackin know. Anyone else wishing to record, please bring your recording devices along. It doesn't hurt to have a back-up!

If you take PHOTOS at the party, PLEASE email them to Wanda & Carlos Clas at: [wand519@aol.com](mailto:wand519@aol.com).

## Our February 23, 2013 Speaker Corporal John Simmons

Corporal John Simmons attended Alfred E. Beach High School in Savannah Georgia, from 1980 through 1982. He was the salutatorian of his graduating class.

He then attended Armstrong State College, also in Savannah, from 1982 through 1988 and majored in Computer Science.

From 1989 through 2006, he got his formal training for Peace Officer at the GA P.O.S.T. He also received supplemental training for P.O.S.T. Instructor, Field Training Officer, and operator of an Intoximeter 5000.

Corporal Simmons worked for the Savannah Police Department as the Beat Officer- Southside/ 4<sup>th</sup> Precinct from 1989 through 2003. He patrolled several residential areas, attended community meetings as the beat officer, and randomly patrolled and justly enforced the laws in various commercial areas of Savannah.

From 2003 to date, Corporal Simmons has worked as the Crime Prevention Officer, also for the Southside/ 4<sup>th</sup> Precinct. His duties include attending community meetings, coordinating exhibits for National Night Out and conducting security inspections, just to name a few.

His interests include being a role-play gamer and designer, computers, bodybuilding, cycling, martial arts, rugby and the Japanese culture.



Photo courtesy of Charlotte Richter

### **"Crime, Safety and You"** with Corporal John Simmons February 23, 2013 Program Notes

1. Criminals target neighborhoods that "look" like they are occupied by people who own nice things and who might be lazy or complacent about their belongings.
2. You are reinforcing a criminal's behavior positively if you are lazy and allow them easy access to your belongings.
3. The goal is to give them negative reinforcement by securing your possessions and not allowing them easy access.
4. If you are installing a deadbolt on your door, make sure it is a double cylinder deadbolt. Keep the door locked with the key and keep the key away from the door area, especially if the door has a surrounding or nearby window. If the criminal breaks the surrounding window, he will not gain access through the door because it will be locked with the key. **DO NOT KEEP THE KEY IN THE KEYHOLE.** (*Window alarms can be a deterrent to a criminal trying to enter through a window.*)
5. Have at least a single cylinder deadbolt lock to the door that leads from your house to the garage.
6. **PHYSICALLY** check to make sure your windows are locked. **DO NOT** assume that you locked them.
7. Sheer curtains really don't block the view in, they block the view out. Open curtains enough during the day to let people know that there is someone home and you can see them. Pull curtains and drapes closed when the sun goes down so, that no one can look into your home.
8. If you can afford it, install an alarm system. Monitor the system regularly to make sure all the components are in working order, including the back-up batteries.
9. Call your local Crime Prevention Officer and have him/her come over before you test your system so that they can help you with the test.
10. If you are going out of town, call your local police department and let them know. They will place your home on the "extra patrol" list. They will ask you some questions, such as how many days you will be gone, how many cars will be in the driveway, what lights will be left on in the house, and your emergency contact information, to name a few. Let a trusted neighbor know that you will be away and the police will be patrolling.
11. Know the people that you might hire to make repairs in your home **BEFORE** they come in. You can contact your local police department to check-up on someone you are thinking of hiring beforehand.
12. Be careful of people who leave flyers on your door or mailbox, and be extra careful of those knocking on your door offering their services.
13. Corporal Simmons reminded us that "it is okay to lie to strangers." Tell them that you "have house-guests" and "you will call them at a later date." This gives you the opportunity to check them out before you hire them.
14. He stressed that confidence can be an asset when you are out and about. A look of confidence can be a deterrent to a criminal. Look people in the eye and make sure you acknowledge those around you. Know your surroundings. He said to know your limitations, but to push your boundaries.
15. Allow yourself time in your locked car to get yourself together and gather your belongings **BEFORE** you get out of the car. Walk or ride to your destination with a sense of purpose.
16. Press 911 **SEND** on your cell phone if you feel threatened by another person. Leave the phone on even if you can't speak. The system starts recording even before the dispatcher answers.
17. If you call 911 and don't need help, explain to the dispatcher that you felt afraid and are now okay.
18. You can get involved with the Citizens Emergency Response Team or CERT. CERT teams can use your knowledge or abilities to check on and help neighbors after a hurricane or storm.

19. **Marty Foxx** suggested getting your neighbors to turn on their porch lights to make sure that you have a well-lit street.
20. **Sandra Bath** suggested you give a contact number to your neighborhood watch or a trusted neighbor in case you have not been seen or heard from for some time.
21. **Editor's Tip-** When you are shopping, try to pick a shopping cart with a "baby safety strap" near the handle. If you must place your purse in a shopping cart while you shop, wrap the "baby safety strap" through your purse handle a couple of times and snap the "baby safety strap" closed. If someone tries to grab your purse and go, they will have a much harder time getting it out of the cart. Always know who is around your belongings. NEVER leave your purse or belongings unattended.

The following is the article that Corporal Simmons used in his presentation. It is reprinted with permission from the Boulder Police Department, Boulder, Colorado.

## Safety for the Disabled

Disabled persons face many physical challenges. This could make them vulnerable to would-be assailants who assume the disabled are incapable of protecting themselves.

People of all abilities can follow these basic safety tips to decrease their chances of victimization:

### Look Out for Yourself

- Stay alert and tuned in to your surroundings, whether on the street, in an office building or shopping mall, driving, or waiting for a bus.
- Send the message that you're calm, confident, and know where you're going.
- Be realistic about your limitations. Avoid places or situations that put you at risk.
- Know the neighborhood where you live and work. Check out the locations of police and fire stations, public telephones, hospitals, restaurants, or stores that are open and accessible.
- Avoid establishing predictable activity patterns. Most of us have daily routines, but never varying them may increase your vulnerability to crime.

### At Home

- Put good locks on all your doors. Sturdy deadbolt locks are best. Make sure you can easily use the locks you install.
- Install peepholes on front and back doors at your eye level. This is especially important if you use a wheelchair.
- Get to know your neighbors. Watchful neighbors who look out for you as well as themselves are a frontline defense against crime.
- If you have difficulty speaking, have a friend record a message (giving your name, address, and type of disability) to use in emergencies. Keep the tape in a recorder next to your phone.

## Out and About

- If possible, go with a friend.
- Stick to well-lighted, well-traveled streets. Avoid shortcuts through vacant lots, wooded areas, parking lots, or alleys.
- Let someone know where you are going and when you expect to return.
- Carry your purse close to your body, not dangling by the straps. Put a wallet in an inside coat or front pant pocket. If you use a wheelchair, keep your purse or wallet tucked snugly between you and the inside of the chair.
- If you use a knapsack, make sure it is securely closed.
- Always carry your medical information in case of an emergency.
- Consider carrying a cellular phone.

## Before You Go On Vacation

- Plan ahead. If you're traveling by car, get maps and plan your route. Have the car checked before you leave.
- Leave copies of the numbers of your passport, driver's license, credit cards, and traveler's checks with a close friend or relative in case you need to replace these papers.
- Put lights and a radio on timers to create the illusion that someone is at home while you're away. Leave shades, blinds, and curtains in normal positions. Ask neighbors to pick up your mail and other deliveries, or put a hold on your mail at the Post Office.

## On Public Transportation

- Use well-lighted, busy stops. Stay near other passengers. Sit by the driver.
- Stay alert! Don't sleep as you ride.
- If someone harasses you, make a loud noise or say "Leave me alone." If that doesn't work, hit the emergency signal.

## Don't Let a Con Artist Rip You Off

Many con artists prey on people's desires to find miracle cures for chronic conditions and fatal diseases. To out-smart those con artists, remember these tips:

- If it sounds too good to be true, it probably is.
- Don't let greed or desperation overcome common sense.
- Get a second opinion.
- Be wary of high-pressure tactics, need for quick decisions, demands for cash only, or high-yield, low-risk investments.

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The Boulder Police Department, together with the Association for Community Living, also offers **Safety First** twice each year to developmentally disabled youth and adults. The program covers such things as decision making, street safety and home safety.  
<[http://www.bouldercolorado.gov/index.php?option=com\\_content&view=article&id=2954&Itemid=4155](http://www.bouldercolorado.gov/index.php?option=com_content&view=article&id=2954&Itemid=4155)>.



## Happy Birthday



### March

Barry Turner - 2  
Thelma Tillotson - 4  
Lavonne Calandra - 7  
Della Simmons - 14  
Glenda Walker - 14  
Terri Dunnermann - 18  
Robert Stinnett - 18  
BJ Vance - 22  
Roy Tillotson - 24

### April

Fred Davis - 2  
Tom Newcomer - 2  
Sissy Morel - 6  
Marty Foxx - 8  
Stuart Robinson - 27

## Member Concerns

Janet DiClaudio, Eunice Newcomer,  
Harriett Merritt, Dot Parkhurst & Barry Turner

*Please keep these members in your prayers.*

## Quote of the Month



*"Tis better by far at the rainbow's end  
to find not a pot of gold but the heart of a friend."  
-Author Unknown*

## Correction

It has come to the attention of THE LIGHTHOUSE that we did not mean to write "Balfour" but rather "Belfor" in our February 30, 2010 newsletter Minutes section on page 2. Our apologies for the misspelling.

**We wish all our CEPESA family and friends  
a most joyful Easter 🌸  
and a Sessa (Sweet) Passover 🌸**

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.

## Good News

*Received this wonderful letter from Marty. Janet certainly is a wonder!!!!*

Jim

*Brenda Mills and I went to visit Janet on Tuesday afternoon. We found her sitting up in bed, watching closed caption TV, and pleased as punch to see us. She got her talking pipe hooked onto the ventilator and just talked a blue streak, so animated and funny. She said she can eat a little by mouth now, but she still uses the feeding tube mostly. Her hearing is quite bad, so we had to write what we said to her; she read it easily and answered. Her brother calls her every day now; that is a great comfort to her, I could see that clearly. She asked about several of our members, concerned about how they were getting along. She does get up and walk a few steps to the chair! She talks about when she's going to go back home. The Eagle Health and Rehab. Place where she is seems wonderful to me; it smells good and the staff was super responsive. They've told her when she's ready to sit up longer, we [several polios] can visit in the group room. She's thinking of entertaining the Red Hat Society ladies there also. They have activities like scrabble and cards which she enjoys. I asked what I could bring next time and she asked that we bring ourselves. She was delighted with Nancy Hess's visit. Keep her cards and letters coming and visit if you can. She's our miracle of the year!*

Marty

From an e-mail from Jim Veccia to all CEPESA members. 28 February, 2013.

## FREE Medications from Publix

Publix is offering a variety of some of the most-often prescribed medications absolutely FREE. It doesn't matter who your insurance provider is or how many refills you need, Publix doesn't even have any forms to fill out. Just hand in your prescription of any of the medications on their list and they will take care of it. The cost to you is ZERO!

Some of the medications on the Publix website\* include:

### Antibiotics-

- Amoxicillin
- Ampicillin
- Cephalexin (capsules and suspension only)
- Sulfamethoxazole/Trimethoprim (SMZ-TMP)
- Ciprofloxacin (excluding Ciprofloxacin XR)
- Penicillin VK

### Ace inhibitor-

- Lisinopril

### and as part of their Diabetes Management System-

- Metformin

\*Please check with your local Publix Pharmacy for changes to the list of medications available in your area.

Available **FREE** to any CEPSA member in need of this unit.

Contact Richard Graham at (912) 728-3393 or Jim Veccia at (843) 837-1230 if you are interested.

## SLIDER BATHING SYSTEM



### Slider Bathing System

	SL100 Standard
Between arms	17.5"
Overall width	21"
Overall length w/push handle	25"
Seat depth	18"
Standard seat to floor	24"
Seat to footrest	17"
Commode clearance	18.75"
Weight capacity	250 lbs

The Slider is a rolling shower chair and tub frame that eliminates the need for costly bathroom renovations. Until now, caregivers and parents of individuals with special needs have had to make as many as six or more transfers to get a child or adult from a wheelchair to the bathtub or toilet. No more!

The standard Slider Bathing System eliminates costly 'roll-in' shower renovations and dangerous transfers in a wet environment. The standard Slider works with any standard bathtub and rolls over any commode. The SLIDER has two swing away arms for lateral transfers, tension adjustable backrest, seat belt is standard, slide out footrest, open front integral skin foam seat for easy access to perineal area and utilizes 5" total lock casters.

The Slider bath chair will easily support a person with mild to more severe levels of physical involvement weighing up to 250 lbs. (114 kg). The Slider bath chair and transfer system would provide exceptional support for individuals with such medical conditions as Spina Bifida (latex free), Muscular Dystrophy, Cerebral Palsy, stroke, heart conditions, and many more.

The Slider rolling bath chair/shower chair consists of a rolling shower chair that interlocks with a removable PVC support frame. When detached from the support frame, the Slider's rolling chassis can be positioned over a standard toilet commode and then without even one transfer from the seat, can be placed next to the tub, interlocked to the frame, and slid right into the bathtub. It's as simple and safe as that! For easy access to the person bathing, the rolling chassis can be removed so the caregiver can help with bathing. When bathing is complete, simply reposition the Slider chassis next to the tub, interlock it with the support frame, and slide the bath chair back onto the Slider rolling chassis. Once locked in place, the Slider rolling shower chassis can be rolled over the toilet and out of the bathroom without the need to transfer the person on a wet surface.

Parents, therapists, and caregivers will love this safe, easy-to-use, and especially, cost effective rolling transfer/bathing system. Transfers will be limited, caregivers will reduce back strain and injury, other family members will maintain bathtub/shower/toilet access, and most importantly, bathing will be easier and safer for individuals with special needs. The furniture grade polyvinyl chloride resin (PVC) tubing of the bath chair and the Slider rolling shower chassis are sure to be long lasting. The nature of the material will resist chips, dents, stains, peeling, fading, rust, and even sustain bacterial growth.

The slider works effectively with most existing standard size built-in bathtubs and toilets.

PVC durable medical equipment is a manufacturer of high quality plastic medical equipment and accessibility devices.

For more information about this product and other available products visit: [www.pvcdme.com](http://www.pvcdme.com)

Reprinted with permission from Tom Roberts, Owner of Assistive Technology Inc. , 08 March 2013.

# A CLARIFICATION OF NON-PARALYTIC POLIO

By Ernest W. Johnson, MD

(Dr. Johnson is editor of the American Journal of Physical Medicine and Rehabilitation. He is a well recognized expert on Post-Polio Syndrome.)



For many years, most physicians have understood that non-paralytic is a loose clinical term implying that neither the patient nor the clinician-examiner reported functional weakness. This determination was often made without the understanding that 50% of the motor units can be lost before a manual muscle grade of four occurs. This means that many patients with acute polio were labeled non-paralytic incorrectly, but certainly in a well-meaning way.

When the polio virus is in the gastrointestinal tract of an individual and causes symptoms, the term abortive polio has been used. This is the condition that confers immunity on the individual and also prevents the carrier state. This is why the Sabin (attenuated, live polio virus) vaccine prevents the invasion of the polio virus into the central nervous system, but not the polio virus from living in the gastrointestinal tract.

In those individuals whose immune systems, for whatever reason, permit the invasion of the central nervous system by the polio virus, a population of anterior horn cells will die. The number of these cells that die will determine whether the clinician will be able to identify paralysis.

In the late 1950s, our electromyographic studies suggested that in all patients who experienced the invasion of the central nervous system by the virus, pain, meningismus, and positive spinal fluid findings revealed abnormal irritability (fibrillation and positive waves) in many muscles that were clinically "normal."

It should be absolutely understood that patients who were told that they had non-paralytic polio did, in reality, have polio which affected their anterior horn cells. Now, 30 to 40 years later, these patients are potentially subject to all of the vagaries and insults to the body that affected other persons with post-polio syndrome.

Reprinted from Polio Heroes of Tennessee, September 2005

Reprinted from Central Virginia Post-Polio Support Group, Richmond, VA; Library of Articles. <<http://www.cvppsg.org/library/>>

# LEG SWELLING

By Professor Elizabeth Dean



Swelling in the legs is a common complaint of polio survivors. Muscles act like a pump. When they contract, blood returns to the heart after being pulled downwards by gravity. Legs with muscle weakness or paralysis have less capacity to perform this pumping action, either when you are walking or when you contract these muscles in the sitting position. Swelling in the legs can be a serious problem for several reasons. First, engorgement of tissue with fluid can be uncomfortable, making clothing fit difficult; it can become chronic and it is important to bring it to your doctor's attention. Here are some things to try to reduce leg swelling after your doctor has ruled out other causes.

If you are able, move your ankles up and down when you are sitting, and bring your knee up towards your chest. These movements will be helpful.

If you are unable to actively move your leg, a family member or friend can passively move the leg for you, so your hip and knee bends; this is best done when you are lying down so the fluid can move towards your chest cavity more easily. The leg should be moved in a rhythmic fashion.

Put your feet up whenever you are sitting down. Don't be proud - just ask for a stool or another chair. Before long, people will be anticipating your request and have one waiting for you when you sit down. When you lie down for a rest or sleep, put pillows under the leg so that it is higher than your heart.

Have a family member massage your leg so the fluid moves up towards your heart. Again, this is best done when you are in a lying position so the fluid can move towards your chest. This massage should not be vigorous, as tight swollen skin is more at risk of abrasion, breaking down, inflammation and cellulitis. The leg should not be massaged if skin breakdown or redness is present.

Avoid restrictive clothing, including corsets, tight underwear, tight socks and shoes. Consider support stockings (for both men and women) that extend up over your knee. If you have extensive swelling, the stocking will have to go up to your groin; otherwise



—ballooning of the fluid will occur where the stocking ends. These stockings must be properly fitted by a physiotherapist to ensure that they are an appropriate fit, that they are not too loose or too tight, and to teach you how to apply it so it does its job properly, when to wear it for a period of time, then take it off for a period of time and then reapply it.

Passive mobilizers of the legs are available as well as what is called an intermittent pneumatic stocking. These, however, are not typically available to the public, but may be used by a therapist if your swelling is extensive or does not resolve the problem with suggestions above.

If you are a diabetic or have glucose intolerance, your skin is even more at risk of breakdown and infection. Your doctor should be following you closely. Both your doctor and physiotherapist should make recommendations regarding foot care.

**Professor Dean** is head of the Post Polio Clinic at the University of British Columbia.

Reprinted from *Post Scripts*, FL, May 2010 and *Polio Deja View*, VA.

Reprinted from SECOND TIME AROUND, JULY 2011 - Publication of Boca Area Post Polio Group, Boca Raton, FL



At the end of last year, LIFE came together with other local organizations to form the Chatham County Disability Task Force. The primary goal of the Task Force is to develop ways to communicate emergency information to hard-to-reach populations throughout the county.

To help accomplish that goal, we've scheduled a roundtable discussion on Wednesday, April 10, that will allow residents with disabilities to learn more about emergency planning and give local emergency planners an opportunity to listen to concerns that residents with disabilities may have regarding emergency preparedness.

Additional information can be found adjacent. We'd appreciate your help in getting the word out about the forum.

Warm Regards,  
Fran Todd  
Executive Director  
Living Independence for Everyone (LIFE), Inc.

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

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## Chatham County Disability Task Force Media Advisory

### Emergency Planning Roundtable for People with Disabilities Slated for April 10

**WHO:** Chatham County Disability Task Force, a coalition of community organizations created in 2012 to focus on communicating important information before, during, and after emergencies to hard-to-reach populations.

**WHAT:** Open forum for people with disabilities to learn more about emergency preparedness and planning from local officials and for emergency planners to better understand the needs of the residents with disabilities.

**WHEN:** 1 - 4 p.m., Wednesday, April 10

**WHERE:** Trinity Lutheran Church, 12391 Mercy Blvd., Savannah

**WHY:** Emergency planning is essential, particularly for those living in coastal Georgia where natural disasters such as hurricanes can occur. Personal preparedness is even more important for those living with disabilities that may have additional requirements that need to be addressed in the event of a crisis. The Chatham County Disability Task Force will hold a roundtable discussion for residents with disabilities of Chatham County at 1 p.m., on April 10, at Trinity Lutheran Church in Savannah.

Brief presentations will be given by panel members at the event followed by a question and answer session. Panel participants will include:

- John Kim, Advocate Specialist, Georgia Council of the Hearing Impaired (GACHI)
- James Aberson, Coordinator, Americans with Disabilities Act Coordinator, Chatham County
- Kim Harrison, President, Savannah Chapter of Georgia Council for the Blind and Board Member of Living Independence for Everyone (LIFE), Inc.
- Clayton Scott, Director, Chatham Emergency Management Agency (CEMA)
- Annette Neu, Director of Emergency Preparedness and Response, Coastal Health District
- Carmen Young, State Nurse Leader, American Red Cross

For more information contact Kelly Harley, CEMA, at 201-4508; Fran Todd, LIFE, Inc. at **920-2414**; or Sally Silbermann, Coastal Health District, at **644-5217**.

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Information Submitted by Cheryl Brackin on 05 March 2013.

# How to Prevent Further Disability in Polio Survivors

By Julie K. Silver, MD



The thought of becoming increasingly disabled as aging progresses is something that we all fear. For polio survivors, particularly those who are experiencing symptoms of post-polio syndrome (PPS), the fear of not knowing what the future will bring may be overwhelming. Although it is important to treat the symptoms of PPS, there are many other reasons why polio

survivors may become further disabled. This article addresses three major reasons why polio survivors may experience further disability as they age, and how to prevent this from occurring.

## #1 - Systematically addressing and treating all potentially serious medical conditions.

The symptoms of PPS (ie., new weakness, fatigue, pain, cold intolerance, breathing and swallowing problems and muscle atrophy) may occur with many diseases as well as with a prior history of polio. Moreover, some of these "other" diseases may be life threatening whereas PPS generally is not. Therefore, anyone experiencing symptoms consistent with PPS should have a thorough work-up by a physician who is a polio expert in order to eliminate other, more serious or potentially curable medical conditions that many mimic symptoms found with PPS.

If all other conditions are ruled out and the diagnosis of PPS is made, polio survivors should remain alert to the onset of new symptoms or worsening of previous symptoms. A re-evaluation is indicated with either of these scenarios in order not to mistake the onset of a new medical condition for PPS. For instance, if a polio survivor has a long history of muscle pain in his arms and legs and is now experiencing abdominal pain, this warrants investigation. New abdominal pain may be a minor problem involving constipation or may herald the first warning signs of a life-threatening condition such as colon cancer. Therefore, despite having had a thorough evaluation by a polio doctor and being diagnosed with PPS, any individual experiencing new problems or more severe problems than initially reported should be re-evaluated.

Although PPS rarely becomes life threatening, there are many other medical conditions that may seem like minor annoyances at first, but can escalate into disabling or even

deadly diseases. Some common diseases that are frequently underestimated include high blood pressure (hypertension), high cholesterol levels (hypercholesterolemia) and poorly controlled blood sugar (diabetes). These are examples of diseases that should be aggressively treated in order to prevent severely disabling and potentially life threatening events such as a stroke.

Polio websites and newsletters across the country have often contained information about medication that may exacerbate the symptoms of PPS. While this is an extremely important topic, it is imperative that polio survivors don't recklessly abandon medications they are taking to control a variety of other serious medical conditions. Anyone who is concerned with possible drug interactions or side effects from a medication should discuss this with the prescribing physician who then has the opportunity to consider alternate treatment approaches. Certainly, the goal is always to have individuals take only those medications that work effectively and cause few side effects; however, in reality this is not always possible. As with all medical treatment, it is ultimately up to the individual taking the drug to decide whether the side effects are worth the benefits. The important point here is that polio survivors need to make **informed decisions** about which medications they will and won't take. **Medications used to treat disabling or potentially life threatening illnesses should not be discontinued even if they exacerbate the symptoms of PPS unless a reasonable alternative is available or unless the individual taking the medication fully understands what may happen without it and makes an informed decision not to use it regardless of the consequences.**

## #2 - Protecting the arms.

There is a direct correlation between the strength of an individual's arms and their ability to care for themselves without assistance. Thus, one can say that the arms are the key to independence and the stronger an individual's arms are, the greater the likelihood that he or she will be independent. Think of it this way - arms are essential for mobility (rising from a chair, transfers, etc.), dressing, bathing, driving a car or even communicating by phone, fax or Internet. While it is true that technology is providing new types of adaptive equipment that will enable individuals with upper extremity weakness to become more independent, keeping the arms strong and injury-free is essential.

Unfortunately, protecting arms and avoiding injuries to them may be easier said than done - particularly in those individuals who rely on their arms to compensate for trunk or leg weakness. For instance, polio survivors who rely on their arms for mobility purposes are prone to having arm injuries such as rotator cuff problems in the shoulder, nerve injuries at the elbow or wrist, tendonitis and even muscle

strains and ligament sprains. For example, a polio survivor who uses a cane or crutch to walk puts pressure on the hand and arm that holds it. Further overuse of the arm holding the cane is very common due to putting pressure on it repeatedly in order to rise from chairs and commodes. The combination of using the arm during ambulation and transfers as well as for everyday activities may prove to be too much and an injury or new weakness can result. Studies have shown those polio survivors who use wheelchairs or other assistive devices such as canes and crutches have higher than average risk of injuries to the arms.

Although injuries to the arms may be inevitable, early medical attention can do a lot to mitigate these injuries. On the other hand, ignoring pain, tenderness, swelling, numbness or tingling in the arms and hands can lead to serious permanent injuries, which may in turn lead to further disability. This is because injuries are nearly always easier to treat in the early stages and those injuries that are allowed to progress to a more advanced stage become much more difficult to cure.

The good news is that many, if not most, arm injuries are treatable and often curable. The cure may involve rest from activities that exacerbate the symptoms, splints, medications, injections, physical and/or occupational therapy, and in some cases even surgery. The earlier an injury is treated, regardless of the injury, the more likely that treatment will be successful.

**In summary, for those polio survivors who have become accustomed to a variety of aches and pains, it is important to recognize that many of symptoms that occur in the arms are treatable and potentially curable and therefore should not be ignored. Moreover, leaving injuries in the arms untreated may lead to significant disability that may be permanent.**

### **#3 - Avoiding falls.**

Falls resulting in serious injuries are one of the leading causes of disability in individuals as they age - regardless of whether they have a pre-existing disability. One of the most important things to remember about falls is that they are generally "preventable occurrences" rather than "accidents." Common injuries associated with falls include minor bruises and abrasions, broken bones and head trauma that may lead to permanent brain damage. Obviously, all of these injuries can potentially be disabling. However, even if an individual simply has a fear of falling (without necessarily having experienced a fall with a serious injury) this may be equally disabling by leading to social isolation because they are afraid to go out. Therefore, regardless of whether an individual has fallen or is simply worried about falling in the future, this may significantly impact their quality of life.

Preventing falls is much easier to do when one

understands how and why most falls occur. Certainly there are some absolutely unavoidable situations where preventing a fall would be virtually impossible, however, as noted above, most falls are avoidable with a little forethought and planning. Falls occur for a number of reasons, but in general they can be broken down into two categories. The first category includes falls that occur due to a problem with the way an individual's body works. This may be due to weakness, loss of balance, problems with vision or hearing, dizziness, etc. The second category includes those falls that occur due to a problem with the environment. This would include falls due to hazardous weather conditions, slippery surfaces, cluttered rooms, uneven surfaces, etc.

In order to prevent falls, both categories - your own body and your physical environment- should be carefully considered and changes made as deemed appropriate. Medical experts who specialize in treating polio survivors can be excellent resources for information on how to prevent falls as it applies to individual needs. For instance, a polio specialist can determine whether new braces are needed, if physical therapy might improve balance and strength, etc. They can also recommend that a physical or occupational therapist visit your home or workplace in order to evaluate how to make the environment safer (and offer suggestions on how to protect your arms!). Polio doctors and other healthcare providers can offer invaluable advice on how to prevent falls and subsequent disability.

For those individuals who trip occasionally but haven't fallen (yet), it is important to remember that a trip is less than a step away from a fall. Anyone who is experiencing tripping or falling or who is concerned that they may fall should seek medical attention. Most falls are preventable which means that serious injuries that lead to further disability in polio survivors can generally be prevented!

Preventing further disability in polio survivors is critical. Fortunately, there are a number of things which can be done to prevent further disability but to do this requires a thoughtful intelligent approach by the individual as well as appropriate medical intervention from physicians and other who are experts in the care of polio survivors. The three ways mentioned in this article to prevent further disability in polio survivors (treating all serious medical conditions, protecting the arms and preventing falls) are certainly not the only ways to prevent further disability, however, they are a good place to start. Moreover, polio survivors who take the initiative to try and prevent further disability will likely experience fewer problems in the future and in turn, this may give them a measure of comfort about what the future will bring.

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Reprinted from "Polio Deja View", Central Virginia Post-Polio Support Group, Richmond, VA; Library of Articles. <<http://www.cvppsg.org/library/>>  
Reprinted from "The Seagull", newsletter of the Triad Post-Polio Support Group of Greensboro, North Carolina; May, 2003.

## **CONTRIBUTIONS**

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Please complete this form and mail it along with your check to: **CEPSA, Marty Foxx**

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

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Name of member

*Thank you for your support and encouragement.*



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*Shining Light on Post-Polio Health*

CEPSA's next meeting is on  
Saturday,  
March 23, 2013  
10:30 AM  
at The Exchange on Waters  
6710 Waters Avenue  
Savannah, GA 31406

