



THE LIGHTHOUSE

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

October, 2012 Newsletter

www.coastalempirepoliosurvivors.org

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The President's Message...

Are you disabled: physically or mentally impaired to the point of not being able to function normally? Many conditions cause mild to severe disability, ranging from blindness and deafness to atrophy and paralysis. Post-polio syndrome is one cause of disability. Fatigue, breathing problems, muscle spasms, muscle weakness and muscle pain decrease our ability to walk and use our arms to perform our daily chores.

Most polio survivors have done their best to be as normal as possible. It is very difficult for them to admit that they are disabled.

One thing that we do admit to is that we are frequently in pain. That is because everyone (able-bodied and disabled) has experienced pain during their lifetime. Physical, mental and/or emotional pain from mild to severe affect our ability to function every day.

The subject of our program this month is managing physical pain by our New Member Chair, Harvey Varnadoe, RN. He will be allowing time to answer your questions at the end of his presentation. I hope to see all of you there.

Janet DiClaudio
President

The Big Four Polio Painful Body Parts

Polio Shoulder Because polio survivors usually have more leg than arm muscle weakness, they use their relatively stronger uppers to compensate for weaker lowers. So, when getting up out of a chair, climbing out of the bath or walking using crutches, the arms take the freight. The joint that complains most is usually the shoulder, the pain typically caused by bursitis or tendonitis. Sometimes, shoulder pain and an inability to lift your arm directly upward in front of you may be signs of a rotator cuff tear that could require physical therapy or, possibly surgery.

Polio Neck Polio shoulder can also be a part of polio neck, when the muscles that move the head and those that "shrug" the shoulders upward, go into spasm due to overuse, weakness and poor posture. Polio neck is also the number one cause of headaches in polio survivors.

Polio Wrist Polio wrist is usually caused by carpal tunnel syndrome, the squishing of the nerves that pass across the wrist. Polio survivors have much more carpal tunnel syndrome than the general population because pain in the wrists develops in the same way as polio shoulder - from overuse of joints - and in the case of wrists, with repeated hyper-extension (bending backward) as you push yourself upward from sitting to standing or walk using crutches.

Polio Hip Pain in the hips also is often the result of bursitis or tendonitis caused by weak hip muscles trying to keep you from wobbling back and forth. Polio survivors, and many doctors,

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Next Meeting
Saturday,
October 27, 2012,
10:30 AM

immediately assume that all hip pain is due to arthritis. Polio survivors can have arthritis, but hip pain is almost never caused by arthritis. Again, it is irritated tendons and ligaments that are making you hurt. What's more, what you call hip pain may actually be caused by low back or butt muscles going into spasm as they try to compensate for weak leg muscles.

What to do about the big four? Since pain is triggered by overuse, you need to take the load off of angry joints, their weakened muscles and nerves and their abused ligaments and tendons. Raising the height of chairs, using a toilet booster seat with handles, grips or a frame to help you stand and using a wide tub bench instead of standing in the shower or hauling yourself in and out of the tub will take the load off your upper body.

Once you are up, using light-weight Loftstrand (cuff) crutches is better than using nothing or even a cane. If you have "polio wrists," crutches that have foam-covered handles or hand grips shaped to evenly distribute weight across your palms could be a big help (see www.walkeasy.com). Crutches are also helpful for polio hip since they balance you from front to back and side to side, taking the load off of strained tendons and ligaments and weak hip, back and butt muscles. Of course, rolling in a power wheelchair or scooter is better than walking to ease all post-polio pain.

If taking the load off isn't helping enough, bursitis, tendonitis and muscle spasm can be treated by a physical or occupational therapist with ultrasound, heat, ice, deep muscle massage, biofeedback or training for proper posture or gait. Your doctor may want to try a non-steroidal anti-inflammatory drug like ibuprofen or Celebrex*. However, oral steroids should almost never be used to treat bursitis and tendonitis since their side effects are very unhelpful for most polio survivors. However, a few injections of cortisone and a local anesthetic into a joint or a muscle, followed by the above therapies, can knock down inflammation and prevent spasm. Local injections of cortisone in the wrist can also help rescue inflammation and swelling in those with carpal tunnel syndrome.

**Remember that the best remedy is to NOT OVERUSE in the first place. If you start feeling pain or joint discomfort, that is the time to stop!! Rest is the best and easiest remedy for the BIG FOUR.

***PLEASE DISCUSS THIS MEDICATION CAREFULLY WITH YOUR DOCTOR, IF PRESCRIBED.**

Originally reprinted from New Mobility Magazine, June, 2006 and "Second Time Around" newsletter from the Boca Raton, FL PPSG, July, 2008
Reprinted from "Polio Deja View", Central Virginia Post-Polio Support Group, Richmond, VA: Aug-Sep 2008.

General Meeting Minutes September 22, 2012

President Janet DiClaudio called the meeting to order at 10:49 am and welcomed everyone back.

Cheryl Brackin led the Pledge of Allegiance.

The inspiration was given by Terri Dunnermann who read a poem, "Handwriting on the Wall," author unknown.

Minutes from the June meeting posted in our newsletter were approved as written.

The Treasurer's report was given by Marty Foxx who highlighted the past 3 months of operations. The report was approved as

presented. She also read a letter from Judy Frick, who also made a donation to CEPESA. Harvey reported that a new member Katherine Johnson passed away.

Committee Reports:

No updates were given by Committee Chairpersons. A word of thanks was extended to Carlos and Wanda Clas for another excellent newsletter.

Old Business:

Rotary: Tom/Harvey have been talking with the Skidaway Rotary about doing a bathroom modification for one of our members. They will make an on-site visit the the home of the member as this project progresses.

Meeting location: The next meeting will be at Barnes Restaurant. There is no meeting in November, and the December event, our banquet, will be at the Hilton Garden Inn. The Bull Street Baptist Church was mentioned as a possible meeting location for 2013. Cheryl agreed to visit the site.

New Business:

Nominating Committee: Janet reported that the chairman will be Jim Veccia with Diane Davis, Richard Graham and Dan Shehan. They will present a slate of nominees to be voted on at the October meeting for the positions of President, Vice President, Secretary and Treasurer. Installation of officers will take place at our December banquet.

Accessibility Guide Update: Dan reported that the guide will be ready in January 2013. This will be the second edition, which is being revised by SCCDI and LIFE. The restaurant section is being updated by LIFE. If anyone has a suggestion of a business interested in placing an ad in the guide, Dan should be notified. The guide is distributed at all the visitor centers in the area. It was suggested, if possible, to put the Accessibility Guide link in our CEPESA web site.

Polio Stories: Janet reminded everyone we should document our life stories. If you don't like to write, you can use a recorder or ask another person to interview you. Jim at a previous meeting stated that the Smithsonian is interested in a copy of our "Book of Memories." Diane Davis, maintains this book; you may borrow it at any time.

Fund-Raising: Marty reported that we have submitted our application for the Knox grant. Janet suggested that we all think about other fund-raising ideas and share them at the next meeting.

Directory: Janet asked that Care Team Leaders verify the member information in the current directory, when next calling active and inactive members.

Janet reported she will be moving to Hilton Head for 6 weeks while her current residence at River's Edge goes through a renovation. Her communications access may be limited; however Jim Veccia will assist if needed.

Other: Harvey gave a short talk about how his brace has given him some added strength. Marty shared that pool exercise increases her energy level. A word of caution is to know and learn your abilities.

The meeting was adjourned at 11:47 am. At that time we began our program of Sharing our Strengths. SOS was led by Janet, reviewing Personal Emergency Response Systems and Cheryl/Harvey covered the topic of Accessibility. All the leaders did an excellent presentation and had handouts.

Respectfully submitted,
Michael Dunnermann, Vice-President/Secretary

Attendance:

Cheryl Brackin, Carlos Clas, Wanda Clas, Della Simmons, Janet DiClaudio, Terri Dunnermann, Michael Dunnermann, Diane Davis, Charlotte Richter, Larry Richter, Harvey Varnadoe, Delores McCall, J.E. McCall, Tom Schendorf, Marty Foxx, Sandra Bath, Marge Lampke, Jim Lampke, Brenda Mills, Richard Graham, Dan Shehan and Sissy Morel.

Our October Meeting



Pain Management

Our October meeting will focus on pain management. CEPESA member Harvey Varnadoe, RN, has graciously volunteered to share his professional knowledge about this subject. We thank Harvey for helping us understand a very common topic amongst us.

Harvey:

- ✓ was born in Telfair County, Georgia and was the fifth of six children in his family.
- ✓ contracted polio at thirteen months of age. Polio affected his left arm and right leg.
- ✓ graduated from high school in Telfair County, Georgia. During this time he managed to overcome the weaknesses from polio and to play baseball.
- ✓ married Skeet Bennett and was blessed with three sons.
- ✓ worked in building materials sales and insurance sales for many years.
- ✓ had a midlife crisis, attended college and became a nurse. As a nurse he worked primarily in ER and critical care.
- ✓ began to experience some early symptoms of post-polio syndrome in 2007. It was on May 29, 2009 that he woke up to find that his right leg would no longer support him enough to walk unaided. Even with a brace made with the newest technology that helped him walk, Harvey found that his beloved career as a nurse had come to an end.
- ✓ has kept up his license since May, 2009. He tries to keep up with topics in nursing and medicine, especially in the areas that have impact on people with post-polio syndrome.
- ✓ went to a seminar in February of this year on the latest advancements in pain control for doctors and nurses. He will be giving his talk based on what he learned in this seminar.

**We will meet on Saturday, October 27, 2012,
10:30 AM at Barnes Restaurant,
located at 5320 Waters Ave., Savannah, GA 31419.**

World Polio Day, a day to remember



World Polio Day brings people together to remember the birth of Dr. Jonas Salk, the man who led the first team to develop a vaccine against polio.

It was the development of this vaccine, and its successor oral polio vaccine, that enabled the world to embark on an ambitious journey – the eradication of polio.

Every year on 24 October, people around the world shine a spotlight on the importance of global eradication.

World Polio Day is an opportunity for the polio eradication community to renew its promise to future generations. Now that 99% of the work is done, and most children born today live free of the threat of polio, it is more important than ever that the entire world remains committed to the disease's eradication.

On World Polio Day, we think of the many children who have been paralyzed by polio this year, who would be walking today if polio had been eradicated.

We also think of the many, many volunteers who help to vaccinate children in the field. They are the true heroes of this effort. They often have to dodge bullets in the conflict areas where they operate, they dive into the toughest urban slums in the world and track under sweltering suns... This is foreign aid at its most heroic.

The Global Polio Eradication Initiative is supported mainly by the World Health Organization, Rotary International, the Centers for Disease Control and Prevention and Unicef.

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"World Polio Day, a day to remember." [World Polio Day 24/10](http://WorldPolioDay24/10).
Dirk@worldpolioday (Media). Jul 20, 2012.
<<http://wpd.typepad.com/worldpolioday/2012/07/world-polio-day-a-day-to-remember.html>>.



Join Us and Get Involved

You will be receiving or have already been called to fill a position on the Board. Please consider becoming a Board member. CEPESA's Board is mostly made up of members who have served for many years and are not getting any younger. We must get some of our younger and newer members to be more involved. Please give it some serious consideration. If you feel you cannot serve, please join one of our many committees. All committee Chairpersons can use all the help they can get. They made the commitment to serve, why not make their job easier by offering to help them.

Jim Veccia,
Nominating Committee Chairperson
with Diane Davis, Richard Graham and Dan Shehan



Polio: a personal experience

Every day, there is pain. Ann Lee Hussey's right leg is an inch and a half shorter than her left, causing her to limp. Her feet are misshapen, and her joints and muscles ache so badly by the end of the day that it's tough to go to sleep.

And yet within the last decade this 58-year-old has made 20 trips to some of the most rugged and dangerous places in the world— Mali, Nigeria, Chad. Each time, she leads a team of one to two dozen volunteers with the same ambitious goal: to immunize as many children as possible, thereby ensuring that they will not contract polio, an infectious viral disease that can attack nerves and cause paralysis. It's the same ailment that has wreaked havoc on Ann Lee's life. "I get exhausted sometimes, but then I remember: I never want another child to endure what I've gone through," she says.

Polio is not something most Americans think about anymore. Thanks to the vaccine, it has been eliminated in the United States (though there was a small outbreak in 2005). And as recently as 2010 it was on track to become the second disease afflicting humans (after smallpox) to be wiped out entirely. However, as of last year, 16 countries still reported cases of this incurable disease, according to the U.S. Centers for Disease Control and Prevention (CDC).

Ann Lee is determined to keep those numbers from climbing. But it's not easy. She believes that she is afflicted with post-polio syndrome (PPS), a progressive condition that causes muscular weakness, pain, and exhaustion for up to 25 percent of polio sufferers.

PPS can affect the nerves that control muscles and contribute to the rapid aging of those muscles, according to the CDC. "I'm afraid of PPS," says Ann Lee. "But I try not to let the fear control me." Near her home in South Berwick, Maine, she practices yoga, gets massages, and swims to help herself cope with the symptoms. And she endeavors to stay upbeat: "I'm not a 'woe is me' person. I live in the moment. And I believe in what I'm doing. Sometimes I think I got polio for a reason. It has given me more drive, more determination."

A Painful Childhood

Ann Lee was diagnosed with polio in 1955, when she was just 17 months old— three months after Jonas Salk's safe and effective vaccine was released but before it was widely distributed in many states, including Maine, where she grew up. "There was a terrible outbreak in the Northeast that year," she says. "Scared parents sent their kids out of the cities to the country to protect them, though some were probably already contagious. I was the kid in the country who was supposed to be safe."

She developed a fever and began stumbling dramatically. (The polio virus enters the body through the nose or the mouth, multiplies in the throat and the digestive tract, and then invades the bloodstream.) "My mom recognized the symptoms, and

within a few hours she rushed me to the hospital," says Ann Lee. However, the damage was done. Within days she was paralyzed from the waist down.

The full paralysis lasted only a few weeks, but her largely dysfunctional legs remained in pain. For more than a year, her mother massaged her daughter's limbs every three hours, even in the middle of the night, to keep her muscles from atrophying. Eventually Ann Lee endured eight surgeries, many of which were unsuccessful. "In those days, doctors didn't always know what they were doing," she says. She regularly wore a leg brace, and she was confined to a wheelchair after each surgery.

Ann Lee realized that she was not the same as other children. When she lost her balance and fell over, her four older, healthy siblings would rush to pick her up. "But other kids could be very mean. They would imitate the way I walked," she recalls. "I remember that in fourth grade, I decked a girl for doing it. She never made fun of me again."

The social ostracism grew worse as she got older. During a dance in the gymnasium when Ann Lee was about 12, students were playing a game in which the girls each tossed a shoe into the middle of the gym. "A boy who liked you would pick it up and bring it back to you and ask you to dance," says Ann Lee. "My clunky orthopedic shoe was the only one that didn't get picked up. I was sitting in the bleachers with one bare foot and couldn't walk down to get it. A boy finally handed it to me, but he didn't ask me to dance."

She didn't date in high school. Her first serious relationship started when she was 22. It was with Michael Nazemetz, now her husband of nearly 30 years.

Right from the beginning, Michael was accepting of her, says Ann Lee: "He has always treated me as an equal in our relationship. With him, I can even manage a slow dance. Although I admit, now and then I wish I could wear pretty shoes with heels to do it."

Although she was technically able to have children, the couple never did. "Michael was concerned about whether I would be able to carry a baby to term. Many polio victims do have children, of course. But it depends on the severity of the disease, which can affect the strength of your pelvic muscles. And I wouldn't be able to run after a toddler."

Her condition presented obstacles to a career as well. Ann Lee wanted to be a nurse, but her longtime orthopedist advised against it: too much standing involved. "I still regret listening to that advice," she says. Instead, she became a veterinary technician, and she shares a practice with Michael, who is a veterinarian. "I tried to be open to new opportunities— and I'm glad I was. One was waiting for me right around the corner."

Indeed, Ann Lee discovered her current mission by accident. Back in 2000, she accompanied Michael, a longtime member of Rotary International, the global organization dedicated to humanitarian efforts, to an event. There she learned about the group's work combating hunger, improving health and sanitation, and eradicating polio. "For the first time, I realized how involved the group was in fighting the disease. Later I went to a Rotary information session about their immunization trips to developing countries, and I signed up immediately."

On the excursions, UNICEF and the World Health Organization supply the vaccines and Rotary provides volunteers who administer them. Rotary also alerts local communities that the vaccination team will be in the area. Like all the volunteers, Ann Lee pays her own travel expenses.

In 2001 she embarked on her first polio-immunization trip to Delhi, India. "I was pretty nervous," she says. "I had only been out of the country once, when I went to Canada. The flight seemed so long; India was so exotic."

The experience was eye-opening: "Moms walked for miles with their children, then lined up by the hundreds- all to get their kids vaccinated," Ann Lee recalls. She knew then that she would be making many more of these journeys. "Since there's no cure for this disease, prevention is everything," she says.

On that trip, Ann Lee also found herself drawn to helping the survivors of polio, who live extraordinarily challenging lives. At a local rehabilitation center, staff members paraded out a group of child polio victims to show Ann Lee and the other volunteers how they assist them with braces and crutches.

"One of the kids was a little girl of about nine, with a beautiful smile that I can still see today," says Ann Lee. "She had the same thin, wasted leg that I had and wore the same heavy brace that I did at that age. Looking at her, the memories were overwhelming. I lost it and started to cry. No child should have polio today. Not when it is preventable by a few oral drops that cost just 60 cents."

Ann Lee's commitment to polio sufferers has only grown stronger over the years. In February 2008, she met a young Nigerian girl, Uma, 11. In her rural village, Uma did not receive the physical therapy and the leg braces that she needed. Consequently, her pelvis was too weak to support her spine and she was unable to stand upright. Her hands were severely calloused because she crawled around on all fours, as polio survivors are often forced to do in poor nations.

"Many polio survivors in these countries are treated like dogs," says Ann Lee. "They are physically and mentally abused and forced to beg to survive. Or they're locked away. Few women who have had polio will ever marry."

Uma longed to go to school, but the nearest one was eight miles away. Local children hiked there and back every day. Uma, of course, wasn't capable of making the trip. Ann Lee, moved by Uma's plight, took action. On subsequent trips, in November 2008 and March 2009, Ann Lee relentlessly charmed and lobbied the local governor until a school was built in Uma's village. The next time she returned, in September 2010, she was gratified to find a large sign in front of the two-classroom building: ann lee nomadic school for the fulani tribe. Nearly 300 children, not just polio victims, now attend that school.

Meeting Countless Challenges

That sort of success helps Ann Lee get through the immunization trips, which can be punishing, both physically and emotionally. The weather is often scorching: Mali, 115 degrees; Nigeria, 110. The terrain is unforgiving; Ann Lee has navigated through millet fields, over rickety bridges, and through slums. She has dealt with bedbugs, food poisoning, and numerous bumps and scrapes.

In some more volatile locations, there is also the threat of violence. In Mali, just after Ann Lee visited in November 2011, three foreign tourists were kidnapped and one was killed, possibly by a group affiliated with Al-Qaeda. In Nigeria, where she often travels, ethnic clashes between Muslims and Christians have triggered multiple massacres.

What's more, she and her team have to convince locals that they are there truly to do good. In northern Nigeria a few years ago, Ann Lee says, some religious clerics spread the word that the American vaccine would render children infertile. To prove to the villagers that there was nothing to fear, volunteers made a show of taking the oral drops themselves before inoculating the kids. "I have had women come to me in secret, asking to have their children immunized- as long as their husbands never find out," Ann Lee says.

During the immunization trips, Ann Lee finds that locals do not believe Americans can have polio, "because we live in a rich country," she says. "But when I roll up my pants and show them my legs, it's obvious. I explain that Americans didn't always have the vaccine. And I explain why we need to protect their children."

Seeking lasting change

On just one trip to Nigeria, Ann Lee and her team immunized 10,655 children. Yet she is modest about her accomplishments. "I'm an ordinary woman, not Mother Teresa," she says. "If I've touched thousands of lives, so have the American volunteers who come with me- including a woman of 86 who was a real trouper. For me, and I think for them as well, it's a privilege to do this work."

Her dream now is to return to Nigeria and build a rehabilitation center for those afflicted with polio: "With help, polio victims can get up off all fours. We can help them stand upright and give them back their dignity." She has \$350,000 to raise, but characteristically she isn't daunted by the prospect of coming up with that vast sum. She has conquered worse odds. Plus, she knows that change can happen. She thinks back on her last visit to Nigeria, which she made about a year and a half ago.

"This time I was able to see Uma in her classroom," says Ann Lee excitedly. "She called out to me in English and said she was so happy to finally be in school. Before, she and I had always spoken through an interpreter. We were both thrilled by how far she had come."

It seems fitting, then, that Ann Lee ends her e-mails with a famous quotation from Jonas Salk himself: "Hope lies in dreams, in imagination and in the courage of those who dare to make dreams into reality."

Learn about the United Nation Foundation's Shot@Life Campaign, and how you can help this vaccine program.

Photo Credit: Chhandak Pradhan

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"Polio: a personal experience." [Global Citizen](http://www.globalcitizen.org/Content/Content.aspx?id=cc2861d9-c4a4-40cd-a662-8d557468b343&icid=maing-grid10%7Chtmlws-main-bb%7Cdl3%7Csec1_lnk3%26pLid%3D211327). Jane Atkinson (Media). Aug 03, 2012. <http://www.globalcitizen.org/Content/Content.aspx?id=cc2861d9-c4a4-40cd-a662-8d557468b343&icid=maing-grid10%7Chtmlws-main-bb%7Cdl3%7Csec1_lnk3%26pLid%3D211327>.

To read an additional article about Ann Lee Hussey, please visit: <http://www.spryliving.com/articles/battling-polio-at-home-and-abroad/>
Link submitted by CEPESA member Delores McCall.



Question: Is there a definitive medical position if polio survivors should take the flu vaccine each year? Last year when I went to get the vaccine, the staff notified me that Guillain-Barré syndrome is one of the risk factors of the vaccine. Should one not take the vaccine if you have a history of paralysis?

A: My opinion is that there is no evidence to say that having a history of paralysis (residual muscle weakness) after poliovirus infection would raise your risk of new paralysis or other complications after flu vaccinations. Recently the question of risks to polio survivors from taking the new 'shingles virus' vaccine was raised among the PHI Medical Advisory committee members. The unanimous consensus was there was no known reason to anticipate increased risk for polio survivors.

Question: I have concerns regarding the H1N1 vaccine. Are polio survivors considered an at-risk group?

A: Based on my reading of current public health updates, people who had polio earlier in life are NOT considered 'high-risk' for developing H1N1 flu. I suggest that you consider receiving the vaccine when it is available to the general public, if you are a polio survivor with significant respiratory compromise (reduced pulmonary function), or if your general health is poor from heart or kidney problems, or if you will be around many young children as a child care worker or health care professional. I recommend that you consult your family physician who knows your complete health history, and after doing a little homework of your own, make the decision in consultation with him/her.

PHI recommends the following sites.

This list was sent via email to all PHI Members who have an email in our records. If you are a Member and did not receive it, please send your email address to info@post-polio.org and set your computer to receive emails from info@post-polio.org, so they don't end up in spam.

- One-stop access to US Government H1N1, avian and pandemic flu information (www.flu.gov)
- 2009-2010 Seasonal Influenza Vaccines from the US Food & Drug Administration (www.fda.gov/ForConsumers/ConsumerUpdates/ucm100139.htm)
- CDC: Influenza (Flu) from the Centers for Disease

- Control and Prevention (CDC) (www.cdc.gov/flu/)
- The Lancet's H1N1 Resource Centre from collaborative effort by the editors of over 40 Elsevier-published journals (www.thelancet.com/H1N1-flu/)
- Pandemic (H1N1) 2009 from the World Health Organization (www.who.int/csr/disease/swineflu/en/)
- Stopping the Spread of Germs at Home, Work & School from the CDC (www.cdc.gov/flu/protect/stopgerms.htm)
- INFORMATION FOR PEOPLE WITH DISABILITIES ABOUT H1N1 VIRUS from long-time disability activist and educator Lex Frieden with contributions by Kim Dunn, MD, and Gerard Francisco, MD (The University of Texas Health Science Center at Houston, USA). (www.postpolio.org/H1N1BulletinLF0809.pdf)
- It's Flu Season by Judith R. Fischer, published in Ventilator-Assisted Living (Vol. 23, No. 3) is online at www.ventusers.org.

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Article submitted by CEPISA member Cheryl Brackin.



SHINGLES VACCINATION: Should Polio Survivors Receive One?

Currently there is no experimental data regarding polio survivors getting this vaccine. PHI polled nineteen doctors (experienced in treating polio survivors) about your question and received a variety of responses. The most prudent thing to do seems to be to study the information we provide below, talk with your doctors about your individual circumstances, and then each make your own decision.

THE VACCINE:

In the year 2006 a vaccine called Zostavax® was licensed to prevent shingles in people over age 60. In the clinical trial, the vaccine was successful in 51% of the participants 60 and older and was most effective in those aged 60 to 69. Shingles-related pain may also be reduced in many of

those receiving the vaccine.

PRECAUTIONS:

The Centers for Disease Control says those who should not get this vaccine are people who have had a life threatening allergic reaction to gelatin, the antibiotic neomycin, or any other component of shingles vaccine. They advise those who have severe allergies to inform their doctor about this.

They also recommend certain people do not get shingles vaccine (which contains live though weakened chickenpox virus): Individuals who have a weakened immune system because of HIV/AIDS or another disease that affects the immune system, treatment with drugs that affect the immune system, such as steroids, cancer treatment such as radiation or chemotherapy, a history of cancer affecting the bone marrow or lymphatic system, such as leukemia or lymphoma. Those with active untreated tuberculosis and those who are pregnant or might be pregnant should not get the vaccine.

Individuals who are moderately or severely ill (including those with a temperature of 101.3° or higher) should wait to get their vaccine until they are well.

THE DISEASE:

Approximately one million cases of shingles (also known as *Herpes zoster*) occur in the United States each year. The same virus that causes chickenpox causes shingles. When people recover from chickenpox, the virus lies lurking in the nervous system for the rest of their lives. Certain circumstances (perhaps stress or immune deficiency or something else) reactivate this virus and cause shingles. This usually occurs after age 50.

Shingles may begin as a sensitive or burning feeling in the skin that turns to a rash, usually down a certain nerve on one area and one side of the body. Shingles blisters then form for a number of days before they pop and finally crust over and heal. The entire process can take several weeks.

SYMPTOMS AND COMPLICATIONS:

Fever, chills, upset stomach, and headache can indicate shingles. Very rarely, shingles can result in pneumonia, hearing difficulties, blindness, encephalitis, or death. A common complication of shingles is nerve pain. When this pain continues for more than a month, it's known as postherpetic neuralgia, which occurs in more than 40% of those over 60 who have had shingles. This can be devastating. In some cases, certain medications may be used to alleviate the situation.

INTERESTING FACTS:

People who've had shingles can get it again. Only people who had chickenpox or chicken-pox vaccine can get shingles; the chickenpox virus stays in the body forever. Shingles is not contagious. However, a person who never had chicken pox or the chickenpox vaccine can get chickenpox from someone with shingles.

COST:

A number of factors determine what the shingles vaccine costs individuals. For example, in Omaha, Nebraska, the vaccine is administered in pharmacies for the cash price of \$220. Plan D picks up from \$25 to the full amount, depending on the coverage one has chosen. Medicare itself won't pay for the vaccine, though it will pay a \$20 administration fee. Getting a firm price may take a few phone calls in each separate locality.

ZOSTAVAX® (Zoster Vaccine Live) is a registered trademark of Merck & Co., Inc.

Wise Choices
Feeling Better with Shingles

See your doctor at the first sign of shingles. It often begins as burning or shooting pain and tingling or itching on 1 side of the body, followed by a blistering rash. Early treatment can help shorten the length of infection and reduce the risk of other problems. Your doctor may prescribe:

- Antiviral drugs to help kill the varicellazoster virus.
- Steroids to lessen pain and shorten the time you're sick.
- Antidepressants, anticonvulsants or analgesics to reduce pain.

Things you can do:

- Get enough rest and eat well-balanced meals.
- Try to relax. Stress can make the pain worse.
- Dip a washcloth in cool water and apply it to your blisters to ease the pain.
- Do things that take your mind off your pain. Watch TV, read books, talk with friends or work on a hobby.

Source: NIH News in Health

RESOURCES:

NINDS Shingles Information Page

<http://www.ninds.nih.gov/disorders/shingles/shingles.htm>

Centers for Disease Control and Prevention

(CDC), 1600 Clifton Rd, Atlanta, GA 30333, USA
Public Inquiries: (404) 498-1515 / (800) 311-3435

Shingles Vaccine; What You Need to Know

<http://www.cdc.gov/vaccines/pubs/vis/downloads/vis-shingles.pdf>

**Consult your personal physician
 about receiving a shingles immunization
 and to be sure you have received
 all of your adult immunizations.**

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Happy Birthday



October

Carlos Clas - 1
Billy Ray Washington - 3
Mildred Roberts - 4
Eileen Boyle - 5
Dan Shehan - 6
Hattie Evensen - 7
Skeet Varnadoe - 15
Michael Dunnermann - 16
Linda Munn - 19
Adrienne Stallworth - 31

November

Deno Caloudas - 1
Charlotte Richter - 4
Ann Chance - 11
Pixie Winters - 12
Deloris Manor - 21
Judy Frick - 23
Hilda Fields - 25
Beverly Polin - 25
Velma Underwood - 26

Member Concerns

Ed Dowaschinski, Ann Finley, Lorraine Frew,
Betty Goff, Betty Hope, Patrina Johnson,
Hugh Munn, Eunice Newcomer, Ruth Parham,
Dot Parkhurst, Penny Smith, Barry Turner & Jim Veccia.

Please keep these members in your prayers.

Condolences



CEPSA would like to offer condolences to CEPSA member Ann Chance on the passing of Robert Court Smaridge this past May. Robert was Ann's former husband and "the love of her life." Ann prompted us to "Tell each other you love them everyday." Please keep Ann, Robert, and their families in your thoughts and prayers.

Our Condolences to Henry Cribbs on the death of his wife Katherine Johnson. Katherine was our newest CEPSA member; sadly, we did not get the opportunity to fellowship with her. She was born on March 5, 1943 and contracted polio at 4 months old, in Statesboro, Georgia. She loved to work, read books and watch TV. Our prayers are with Henry and his family.

It is with great sadness that we say goodbye to another CEPSA member George Finley. Our deepest condolences to George's wife Ann, who is also a CEPSA member and polio survivor, and to their family. Our prayers are with them all. Below is a touching note from Ann to CEPSA.

Excerpts from an e-mail from George's loving wife Ann. It reads: *Sadly, I must tell each of you that George passed this morning (September 27, 2012), between 12:30AM and 3:30 AM. He will be buried at Andersonville at 1:30 on Monday (October 1, 2012). He will have a military funeral with honor guard from Fort Benning. His last night was very hard for him and I miss him already!! Last week he received notice from the VA that his lung cancer was caused by an defoliant in Vietnam (Agent Orange). He received 100% compensation. Fondly and sadly, Ann*

Good News

A portion of an e-mail from Cheryl Brackin. It reads: *Bobby Johnson received his prosthesis in July 2012 and now is practicing walking with it. Needless to say, he is overjoyed. Bobby was able to obtain the prosthesis at Positive Images on Waters Ave. Dr. David Puckett, prosthetist/orthotist and CNN Hero in 2008 for his volunteer work in Mexico, fitted Bobby.*

Contributor's Notes

A portion of a note received with a contribution to CEPSA from Cheryl Brackin's sister Sheila Tillman. It Reads: *Happy Fall! My contribution to CEPSA is made in honor of Cheryl's September birthday and as support for your wonderful organization. Take care. Thanks, Sheila Tillman*

A portion of a note received with a contribution from Judy Frick. It reads: *I enjoy receiving your newsletter! You all are doing a great job! May God continue to bless your efforts. Praying also for continued strength and energy. Use this check as needed, and remember: Laugh when you can, Apologize when you should, And let go of what you can't change! AND - Today's trials will be tomorrows testimony. Judy Frick*

Thank You's

A "Thank You" e-mail received from David Troy who was interviewed for the story in our September issue, featuring his late father. It reads: *I thank you and Janet for allowing me to share my story. It is refreshing to read so much about a disease that many people have forgotten. Today's polio survivors are still living from the effects yet battle through every day with a certain dignity that many of us should embrace. God Bless. David Troy*

A "Thank You" e-mail received from Delores McCall. It reads: *We both thank you for your concern and condolences. JE is getting along fair. His brother had been in hospice for about 3 1/2 months when he passed. For about the first 2 months he actually improved. He gained a few pounds and his color improved. He was able to go out with his family and do a few things he enjoyed like having breakfast at Denny's. The family and friends were able to spend quality time with him before he began to really get worse and this progressed rather quickly. We received a card from the support group which we greatly appreciated. Thanks for your support., Delores McCall*

Update / Thank You

In our May issue of THE LIGHTHOUSE, we asked for prayer requests for a soldier, Army Major, Special Forces Green Beret Brian, who is fighting aggressive bladder cancer.. He is the nephew of CEPSA member Eileen Boyle. We are so happy to share this update from an e-mail from Eileen. It reads: *Hi Wanda and Carlos, Thank you so much for your prayers and such a kind response. I have a picture of Brian and his brother, Jamie, who was an Army flight surgeon; and every time I look at them, I pray harder that Brian will overcome this cancer. They both happened to be in Iraq at the same time and fortunately someone took a picture of them.*

The latest news from my brother is that the recent surgery revealed that the cancer is almost eradicated and they will continue with the

BCG treatment. That was MOST welcome news because before that it didn't sound very optimistic. Brian is an optimistic person--he's continuing work on his MBA.
Hugs back to you, Eileen
Please continue to pray for Brian...there is power in numbers.

Prayer Request

Hattie Evensen's brother Vance has just been diagnosed with Myasthenia gravis. Myasthenia gravis is a neuromuscular disorder similar to Muscular dystrophy. Please pray for Vance's health and complete recovery.

 **Quote of the Month**
"Use your imagination not to scare yourself to death but to inspire yourself to live."
-Adele Brookman

Congratulations

A condensed version of Dan Shehan's Polio Story was featured in our September issue of THE LIGHTHOUSE. His full story was featured in his hometown newspaper, The Andalusia Star-News.

Dan's essay got many great responses and can be read in its entirety at:

<http://www.andalusiastarnews.com/2012/09/01/mrs-grundy-scuppernongs-muscadines-in-season/>

Congratulations to Dan for his courage and for sharing his remarkable story.

Our Members in Action

CEPSA member Dan Shehan is part of a team working on the newest edition of the Accessibility Guide. The Savannah-Chatham Council on Disability Issues (SCCDI) and Living Independence for Everyone (LIFE) are working together on the project.

The guide will feature accessible museums, historic sites, restaurants, and tours, free transportation, parking options, and other accessibility information.

Dan asks that if anyone knows of any doctors, pharmacies, restaurants, etc., that would like to have a small ad placed in the guide, to please contact him at:

danshehan33@comcast.net.

The fee for the ad is nominal compared to the exposure their business or office will receive.

If you don't know of anyone who might be interested, ask. Most people will not know that they can advertise in the guide. When you have an appointment or are at a restaurant, take a moment to ask that business owner if they would like to advertise. Tell them that the new guide will now cover all the historic districts north of Victory Drive.

At a previous meeting Richard Graham handed us the "Americans With Disabilities Act (ADA) Checklist For Existing Facilities Form" packet.

Richard makes sure new members become aware of mobility issues that we may face when out in public. The form is vital to

understanding what a barrier-free environment should be.

In the Introduction page, there is the explanation of what the form is for and what the Technical Requirements are. Below is a portion of this Introduction page or page 2:

"Title III of the Americans with Disabilities Act requires public accommodations to provide goods and services to people with disabilities on an equal basis with the rest of the general public. The goal is to afford every individual the opportunity to benefit from our country's businesses and services, and to afford our businesses and services the opportunity to benefit from the patronage of Americans.

This checklist will help you identify accessibility problems and solutions in existing facilities in order to meet your obligations under the ADA.

The goal of the survey process is to plan how to make an existing facility more usable for people with disabilities. The Department of Justice recommends the development of an Implementation Plan, specifying what improvements you will make to remove barriers and when each solution will be carried out: '...Such a plan...could serve as evidence of a good faith effort to comply....'

You can ask Richard for a printed copy or to print out a PDF copy of this form, please visit:

<http://www.dshs.wa.gov/pdf/dbhr/CERTFORMS/ADACHklist.pdf>

Our September meeting focused on Sharing Our Strengths or S.O.S. Two small groups were led by three moderators.

Cheryl Brackin and Harvey Varnadoe led one group with the topic of accessibility. They spoke about the accessibility issues we face on a daily basis and how we can take the initiative to have many of them corrected.

They handed out forms to give to businesses, listing accessibility issues with their establishments. Suggestions were included for correcting the problems. The forms included the Americans With Disabilities Act (ADA) Checklist For Existing Facilities Form that Richard also gives out, the shorter one-page CEPSA form that lists concerns that businesses can consider to make a safer environment for their disabled customers, and checklists developed and used by Physically Challenged Active Adults group of Sun City, Bluffton, SC (shared by Sally Luck). The CEPSA form, available at our meetings can be kept in your car and handed out to businesses as needed.

The second group was led by Janet DiClaudio on the topic of personal emergency alarm systems.

Janet shared her experiences with owning one and how useful it has been in those times of emergency. After several falls, the alarm has become a lifeline for her when alone.

She spoke about how her system works and how other systems are similar. Janet did some research and handed out an internet article that has great information about the basics of personal emergency alarms. The article can be found on the next two pages.

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.

A Buyer's Guide to Personal Emergency Response Systems

By Kate Rauch, [Caring.com](http://www.caring.com) senior editor



Quick summary

Personal emergency response systems, or PERS, are home devices that connect older adults to a 24-hour call center with the push of a button. The transmitter is typically worn on a neck pendant or wristband, and it sends a signal to a receiver that's connected to the home telephone line. When your loved one pushes the button, the staff at the call center evaluates the situation, deciding whether to call an ambulance or a designated friend or family member. With most PERS setups, your loved one can talk with the call center staff from anywhere in the house. ***

This content was originally published by [Caring.com](http://www.caring.com): http://www.caring.com/buying_guides/personal-emergency-response-system-guide, and this excerpt reprinted here with permission.

***Please click on the link above to read the article in its entirety.

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Article submitted by CEPSA member Janet DiClaudio.

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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 Other
- * CEPSA Memorial or Honor Gift - any amount
- * CEPSA Sponsor - any amount

Your contributions are tax deductible and will be acknowledged appropriately.

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

23 East 61st Street, Savannah, GA 31405.

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____ E-mail _____

Are you a relative or friend of a CEPSA member? _____
Name of member

Thank you for your support and encouragement.



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E-mail: CEPSA05@msn.com
www.coastalempirepoliosurvivors.org

Shining Light on Post-Polio Health

CEPSA's next meeting is on
Saturday,
October 27, 2012,
10:30 AM
at Barnes Restaurant,
5320 Waters Avenue
Savannah, GA 31406

