



The Lighthouse

Coastal Empire Polio Survivors Association, Inc.

Newsletter April, 2011

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Shining Light on Post-Polio Health
www.coastalempirepoliosurvivors.org



The President's Message...

We had a very successful meeting (seminar) this past month. Approximately seventy members, doctors, and medical personnel all gathered to hear Dr. Holly Wise give her presentation. No one was at all disappointed! She was probably one of our best speakers. Not only was she so knowledgeable about PPS, but she had a very warm and welcoming personality, that made you feel comfortable in asking many questions. I have already contacted her about getting an evaluation this coming May. If any of you feel that this would benefit you, just e-mail her at wiseshh@musc.edu and she will give you the information needed to make arrangements. I have to thank Diane for spearheading this event and also Janet and Lavonne who helped her out. Great job by all!!

Happy 14th Birthday CEPSA!!

This month's meeting will mark fourteen years since Cheryl, Lorraine, and Shirley Carnell first gathered a group of polio survivors and got the ball rolling for us. I know for myself, I never could have met so many caring people without CEPSA. In my case, here is something that happened to me sixty years ago and over one thousand miles away from Savannah. Yet it helped me find the kind of people I never knew existed. Having lived sixty-two years in New York, it's a different life, not bad, but different. It didn't take me long to see people's kindness to me was without an ulterior motive. When they ask me "How are you feeling?" they actually want to know. It is not just lip service.

Our birthday party will be on April 30th this year. This is the 5th Saturday of the month because Easter weekend falls on our usual 4th Saturday of the month. We will meet in our regular meeting room at Candler Heart and Lung Building. We start at 10:30 AM. After a brief general meeting our program will consist of three of our members telling their "Polio Stories." Then you will be treated to a delicious lunch. This will be handled by Adrienne, Terri, Betty and Lavonne. They did an outstanding job last year, and I'm sure we are in for the same treat this year.

I'm looking forward to seeing everyone there on the 30th!!!

Jim Veccia, *President*

SWALLOWING PROBLEMS

Richard Bruno, PhD

Q. I have trouble swallowing but no one believes me. Food doesn't get stuck in my throat, but seems to lodge somewhere behind my breast bone. I had a normal swallowing study and the doctor doesn't believe I have a problem. But, food sticks and it hurts when it does. Do other polio survivors complain about this?

They surely do. It's hard enough to "swallow" having PPS without doctors refusing to believe you're having trouble swallowing. Most polio survivors at the Post-Polio Institute report having only occasional, mild difficulty swallowing. The difficulty is usually high in the throat: not being able to get down pills, largish pieces of meat and, maybe even more often, difficulty clearing their own secretions. A barium swallow study (eating and drinking food containing barium and having a video taken with an X-ray camera) usually shows mild muscle weakness in the throat or sometimes, as in your case, no problem at all. This negative finding is just like a muscle test of an arm or leg not showing weakness in the doctor's office, even though you feel weaker or even stumble at the end of the day as you get more tired.

Polio survivors also have swallowing problems below the throat. What you describe – food getting stuck behind your breast bone in the esophagus (the tube connecting the throat to the stomach) is not uncommon in polio survivors. The muscles of the throat and esophagus should contract in a coordinated sequence, like a snake's muscles move, to inch food downward and into the stomach. Food gets stuck when the esophagus doesn't contract and its muscles go into spasm, not unlike back muscles going into spasm when your leg muscles are too weak to hold you up. Food usually gets stuck right behind the top of the breast bone. When it does, it's painful and scary. Even if food makes it down to the bottom of the esophagus, in some polio survivors the "valve" just above the stomach doesn't open, preventing food from entering, a condition called achalasia.

Why do polio survivors have trouble with muscles from their throats to their stomachs? Fifty years ago, Dr. David Bodian discovered that every polio survivor had some damage to neurons in the brain stem, the so-called "bulb" of the brain. When this damage was severe and breathing control neurons stopped working, bulbar polio was diagnosed. But the most common bulbar polio symptom was trouble swallowing, not trouble breathing, because the poliovirus also damaged the bulbar neurons that control the vagus nerve, which activates and coordinates muscles from your throat down to your stomach.

Unfortunately, 99 percent of gut doctors have never seen food get stuck in the esophagus and don't know what to do about it. We've found that a low dose of the muscle relaxants Klonopin and Bentyl taken 30 minutes before eating, can relax the esophagus and allow food to slide down more easily.

But wait! There's more! Vagus damage likely explains our 1985 Post-Polio Survey finding that diarrhea, colitis, ulcers and constipation are as much as six times more common in polio survivors than in the general population.

Some polio survivors report that their stomachs don't empty, a condition called gastroparesis. Others have their intestines abruptly stop moving – as a side effect of medication, surgery, a gall bladder attack, or for no reason at all – a condition called paralytic ileus. Often, the muscles of the stomach and intestines get moving again on their own. But, sometimes the drug Reglan is needed to jump-start the stomach and intestines. Also, polio survivors need to try to prevent gut slowing by being careful when taking drugs that are anti-cholinergic (drugs that cause dry mouth) since they block the activity of the vagus nerve.

Finally, polio survivors who have a chronic sore throat, husky voice, or burning in the chest should be evaluated for reflux by an ENT doc, who'll look at the upper throat and vocal cords, and a GI doc, who may do a gastroscopy to look down your esophagus and into your stomach. If you have a gastroscopy, make sure the doc goes light on the anesthesia and uses the anesthetic Propofol, since it's short-acting and allows polio survivors (usually) to wake quickly.

Reprinted from *The Seagull*, NC, March 2009.
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HAPPY BIRTHDAY

APRIL

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

MAY

Lucille Robinson – 13
Vivian O'Kelley – 14
Allen Igou – 17
Wayne Steadman – 17
Dale Merritt – 26
Richard Graham – 31

CONGRATULATIONS!

Delores McIntyre and J E McCall were married on March 19th in Brunswick.
We were able to meet the happy couple at our March meeting.....

MEMBER CONCERNS

TerriDunermann Beverly Jarvis
Ann and George Finley Eunice Newcomer

Please remember and lift up our members with thoughts and prayers.

Approximately seventy people enjoyed Dr. Holly Wise's presentation, "Post-Polio Health Care Considerations for Families and Friends" at Candler Hospital's Marsh Auditorium on March 26, 2011.

She did an excellent job of explaining what families and friends need to know when polio survivors are hospitalized. Some of the topics covered were:

- medical power of attorney,
- visit with the physical and occupational therapists who will be working with the patient,
- home evaluation,
- manual muscle testing, and
- assessment of activities of daily living prior to hospitalization.
- the late effects of polio with ideas on how to treat and manage them.

In conclusion, she answered several questions from the audience.

Janet DiClaudio

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.

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- * CEP SA Supporter - \$25.00 \$50.00 \$100.00 \$300.00

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Name of member

Thank you for your support and encouragement.