



THE LIGHTHOUSE

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

May, 2014 Newsletter

www.coastalempirepoliosurvivors.org

Vol. XVII, No. 5

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The President's Message...



What a grand 17th anniversary celebration we had April 26! It was wonderful to see so many members at the Marsh. Our always outstanding hospitality committee made the day very special as always. Great thanks to Terri Dunnermann, Adrienne Stallworth, Michael Dunnermann, Ed Stallworth, Betty Goff, Gene Goff, and Lavonne Calandra. Alan Page very willingly began working as soon as he arrived and was a lifesaver. My sincere appreciation on behalf of the attendees for all your contributions to make the event such a success.

Lavonne led the Pledge of Allegiance, and Terri gave the inspiration.

Michael read a congratulatory letter from Savannah Mayor Edna B. Jackson, on behalf of the City Council, honoring our 17th anniversary. The framed letter will be available at our May meeting.

Our three speakers who shared portions of their polio stories did a magnificent job. Joan Page, Susan Pineo, and Tom Schendorf gave us insights into their polio journeys. As always, there were laughs and some tears in the audience as they revisited the past. See their talks printed inside the newsletter.

The food was delicious, and the table and room decorations brightened the Marsh. Thank you, Adrienne, for the candle with our CEPSA logo.

What happened to the guest register you signed at the anniversary meeting? It was taken home by Diane Davis, our History Chair. She has an incredible collection of CEPSA memorabilia, including meeting agendas, correspondence, newspaper articles, polio stories, copies of The Lighthouse, DVDs, and more. The archives also contain pictures from various meetings and events.

Early in our existence I proposed that we save the records of this group and donate them to the Georgia Historical Society, when we disband CEPSA. Once this was a dream; now it is doable. We polio survivors and our experiences are an important part of America's and the world's history. Diane has set up a history book for each year of CEPSA. She has done an excellent job maintaining our archives, but this is a huge task. Therefore, our May 17 meeting will be a working meeting called "Updating CEPSA's History Books." We are asking you to help sort and place materials into protective sleeves. For those with issues with their hands and arms, we want you to be with us. This will be a great opportunity to look through the history books that have been completed.

Special thanks to Wanda and Carlos Clas who once again have made significant contributions to the production of this May newsletter.

We need your participation on May 17. Please join us for a different sort of meeting, no doubt one that could bring tears and laughter as we look over our history. Remember that we will be back at the Lewis building and that we are meeting on the THIRD SATURDAY, not the fourth, due to the Memorial Day weekend occurring then.

Cheryl Brackin, President

Next Meeting
Saturday,
May 17, 2014
10:30 AM
at Nancy N. and J.C.
Lewis Cancer and
Research Pavilion
Room 203

Our May Program

The May 17 program is "Updating CEPESA's History Books." We will join History Chair Diane Davis in working on our archives. This is a major task, and we need your help. If you have hand or arm issues and cannot sort and file materials into plastic sleeves, that is not a problem. You will have an opportunity to look through the books Diane has completed. CEPESA has done so much, and you will be able to learn more of our history. Please bring any pictures or articles about CEPESA that you have. If you want them returned to you, be certain to specify that. Your items can be copied and given back. Join us May 17 for a fun, productive day.

Upcoming Meeting Dates

May 17, 2014***

June 28, 2014 @ ***

July & August - No Meetings

August 2, 2014 - Summer Luncheon
noon, Dutch treat

September 27, 2014 @ ***

October 25, 2014 @ ***

November - No Meeting

December 6, 2014 @ Hilton Garden Inn

*** (General Meetings)

@ Nancy N. and J.C. Lewis Cancer &
Research Pavilion, Room 203

Varnadoe Represents CEPESA at Georgia Tech Class

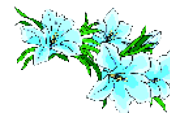
Our own Harvey Varnadoe responded to a request from the Georgia Tech Master's of Science in Prosthetics and Orthotics Class of 2015 to have a CEPESA polio survivor as a subject. Harvey discussed post-polio syndrome with the students and demonstrated how his custom-molded AFO works. He discovered that the class never had made braces for arms. He told them about braces he wore on his arm while he was recovering from polio. Harvey agreed to return each semester to the class. The instructor Dr. Kogler has expressed interest in bringing a few students down for a CEPESA meeting, so they can see various orthopedic issues that we are dealing with. There were 14 students in the class, 4 from Savannah. Harvey received a warm letter of thanks for his enthusiasm and eagerness in teaching them.

Member Concerns

Wanda Clas, Janet DiClaudio, Terri Dunnermann,
Tammie Hooks (niece of Lyn Meeks),
Marie McManus & Barry Turner.

Please keep these members in your prayers.

Condolences



Dear CEPESA family,
My beautiful sister Cheryl Hood passed away Sunday night following a six months struggle to survive. An auto-immune disease called CREST Syndrome had damaged so much of her body, especially her esophagus, lungs, and heart, that she kept aspirating liquids and getting pneumonia over and over again. She suffered through at least 20 years of this disease slowly stealing her strength. She never complained, just kept working and living life. On October 29th she cut my hair, and the next morning she was in the emergency room with respiratory failure. During the next six months she spent only fourteen days outside the hospital: 10 days following being dismissed from St. Joseph's Hospital (which took place slightly over a month ago) and four days under hospice care at her daughter's house in Jacksonville. I am eternally thankful for the few days before her passing; our family was together and for most of that time Cheryl was awake and lucid. She was very tired and ready to let go of a life that had become a burden she could no longer endure. I thank God for the life of my sister, and I take comfort in knowing I will be with her again in heaven. Her obituary will be in the Savannah Morning news Friday through Sunday. Thank you for your prayers for me and my family.

Sandra Bath

From an e-mail from Sandra Bath to Jim Veccia . 06 May, 2014.

Bon Voyage

We wish Marty Foxx and Sandra Bath a safe and enjoyable trip to the Polio Health International Conference "Promoting Healthy Ideas" in St. Louis, Missouri May 31-June 3. This will be the 11th international conference sponsored by PHI for polio survivors and home ventilator users. Marty and Sandra have been asked to share new information they learn.

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.



May

- Bob Parkhurst - 6
- Esther G. Simmons- 13
- Allen Igou - 17
- Becky Cheatham- 19
- Wanda Clas - 19
- Jan Schendorf - 19
- Dale Merritt- 26
- Richard Graham - 31

June

- Jennifer Dupin - 4
- Ruth Parham- 4
- Delores McIntyre - 10
- Ed Stallworth- 12
- Marie McManus - 13
- Charles Orr - 14
- Dot Parkhurst- 14
- Janet DiClaudio - 17
- Harvey Varnadoe - 22

April 26, 2014 Guest Book Signees

Cheryl Brackin, Lavonne Calandra, Ann Chance, Carlos Clas, Wanda Clas, Michael Dunnermann, Terri Dunnermann, Harvey Fields, Hilda Fields, Marty Foxx, Betty Goff, Gene Goff, Richard Graham, Ella Grace Higdon, Lily Higdon, Frances Hodgkins, Archie Ivey, Patrina Johnson, Jim Lampke, Marge Lampke, Sissy Morel, C.L. Orr, Alan Page, Joan Page, Ruth Parham, Paul Pineo, Susan Pineo, Ashley ReBose, Jan Schendorf, Tom Schendorf, Dan Sheehan, Penny Smith, Ross Smith, Kevin Spencer, Adrienne Stallworth, Ed Stallworth, Sharon Underwood, Velma Underwood, Harvey Varnadoe, Gigi Veccia, Jim Veccia, Jamie Warden, Richard Warden, Anna White, Robbie White, Ruby Yearwood.

**CEPSA's 17th
Anniversary Celebration.
April 26, 2014**





My Polio Story

by Joan Page



In August 1945, at age 10, I was visiting with my grandparents on their farm in Freehold Township, NJ, when I became ill. A doctor came to see me and said I had the grippe, another word for influenza. I wasn't getting better, so after a couple of days the doctor visited again. The only thing I really remember is that I had extreme headaches. Not getting any better, my parents took me home. I remember falling, when I tried going to the bathroom. Shortly after that, I couldn't even raise my head off the bed and recall my Dad lifting my head so I could drink from a straw. My parents had a different doctor come to the house, but by the time he arrived they knew what was wrong with me. Immediately I was taken to Monmouth Memorial Hospital, Long Branch, NJ The date was August 10th. I was put in a room with three other persons under isolation. It was hard not to have my parents visit in my room. They had to stand in the doorway.

While in the hospital, I was treated with Sister Kenny's method of hot packs. Sister Kenny, an Australian nurse, devised a treatment using hot packs and gentle exercise. After the hot pack treatment for two days, I was given curare treatments, which meant a needle in the buttocks 4 times a day, to help relax paralyzed muscles. This treatment was developed under the leadership of Dr. Nicholas Ransohoff, from curare, an Indian arrow poison used in ancient times in Central and South America. Curare was used to relax the muscles and severe muscle cramps. I hated to see the nurse come in the room with the needles, as they were so dull and really hurt when injected. After my isolation period was over, the nurses moved me across the hall to a different room, then my parents could come near the bed to visit. After a couple of days, they moved me back into isolation, so a grown man could be moved. I remember being very upset and crying when this happened. A couple of weeks later, I was permanently moved to a different room and started receiving exercises. I also remember the excitement when World War II ended.

During my hospital stay, I went to the physical therapy department daily, which was headed by Dr. Priscilla Ransohoff. I remember lots of painful stretching and exercise. Also, I walked in front of many doctors so they could check my progress and was seen by Sister Kenny when she visited the hospital. Christmas eve I was allowed to leave the hospital, but had to return on Christmas night. I had a wonderful time, received loads of gifts from folks in our area, but was extremely upset about having to return to the hospital on Christmas night. I was able to go home in February, after a six month stay. My Dad converted a chair to help stretch my back while sitting. Also, the physical therapists devised a canvas belt with a pocket that held 12 lead bars, one pound each, which I wore on my weakened right side to help keep my hip from hiking up.

After missing a year of school, I went back without too much trouble. I tried to play basketball and baseball, with someone else running the bases. While in my junior year of high school, I had surgery on my right foot to keep it from hanging down, and in the middle of my senior year I had surgery on the right leg to straighten it. I remember being in the surgery and hearing the doctor asking for screws. They broke the bone, straightened it and screwed it back together. The leg is still straight but the foot started to drop, many years ago, causing me to obtain a brace to hold the foot up. After the surgery, my leg was put in a full leg cast, during which I went on a bus with my senior class to Washington, DC. My cast made it so I was able to go up and down the steps without much trouble. It sure wasn't that easy after it came off. Also, I recall visiting with a young man on a rocking bed who was across the hall. This was a piece of equipment used to help a person with polio breathe, but quite different than an iron lung.

After High School, I got an office job with an insurance agent which lasted nearly ten years. I quit to have my first child, a son and four years later my daughter was born. When my son was one year old we went tent camping. I camped in a tent a couple more times, but found it too hard to be on the ground. After that, we went in a small tent camper, later a small trailer, a larger tent camper and then a larger trailer. I was able to set up all these campers along with a tarp. We joined the National Campers and Hikers Association and formed a local chapter called the Lamplighters. I have moved eleven times. While living in Virginia, my physician suggested physical therapy, which I did for a while. Much of it was in a pool, which I enjoyed. Also, I bought my first scooter, which was wonderful, making it so much easier to go shopping and take my dog for walks around the neighborhood. My next move was to NC. I lived with my mother-in-law for six months, then she left and I remained for another year and a half during which my husband stayed working in VA. While in NC I bought my first walker and a foot pedal for the car. Next, we moved back to VA. This is where I bought a larger scooter, which I am still using, and a lift for the back of my car. I tried doing a little more physical therapy at the local hospital, but couldn't see it doing much good for me. My family physician suggested I see Dr. Jane P. Wooton of Sheltering Arms Rehabilitation Center, Richmond, VA. Dr. Wooton gave me tests to check my muscle strength and suggested I get a Power Chair for use in the house to save what little strength I had left. I got a chair and have been using one ever since. While in VA I joined the Central Virginia Post-Polio Support Group in Richmond, VA. They were a very nice group of people and I received a lot of good tips and information. After moving to Georgia, I considered joining CEPSSA but kept putting it off. Then one day I met Richard Graham at a ball game and he told me about CEPSSA. The rest is history.

My Polio Story

by Susan Pineo



I had just finished a week of overnight scout camp and it felt so good to be home. It was August of 1951 and everything was delightful. I was going into fifth grade, I had friends I could visit on my bicycle, and we had recently gotten a television which opened many new areas of interest for me.

Soon after I returned home I had a stiff neck and then a fever in addition to the stiffness. By Thursday, when our doctor again came to check on me, he said that my parents should take me to the hospital. We didn't go to the nearby hospital but rather they drove me about half an hour away to St. Charles Hospital for Crippled Children. I knew of the hospital because my older sister had performed there with her dance class. I knew about the children attending the recital on stretchers and I knew the children had warm water baths to soak in. And no – it didn't sink in that this was to be my future.

As we drove onto the hospital grounds we saw children wearing football helmets and walking with the help of crutches or canes. I learned later that these were children with cerebral palsy at the hospital for outpatient therapy. My parents left me in the care of the Daughters of Wisdom, a teaching and nursing order. I was placed in a small ward – perhaps ten beds. The treatment followed the Sister Kenny model. I had hot wool blankets placed on me several times a day and my parents were told to prepare for my placement in an iron lung. The fever broke just before that became necessary.

Once the fever was gone I was able to have physical therapy, ride the stretcher into the hot pool (wearing the ugliest old lady's bathing suit many times too large), and attend class. Much of this activity was aimed at keeping my muscles flexible while still strengthening them. My least favorite activity was stretching out the long leg and back muscles. Sit on an exercise table with your knees strapped to the table with a wide, woven strap fastened by a strong leather belt. Touch your head to your knees, five, ten, twenty times. The therapist would set me up and leave me alone. I remember crying and threatening to call my family to come take me home. No wonder they left me alone.

While I was in the hospital my parents were permitted to visit for three hours Sunday afternoons. While still bedridden the nuns would come around just before visiting hours and we could choose a pretty bed jacket and we'd be given a wide satin bow for our hair. My hair was fairly long about to my shoulders. I would get the part down the middle and pig tails treatment. I used to complain to my mother that they pulled my hair so tight, it felt like it was getting ripped from my scalp.

The first six months of 1952 were spent in the hospital. The emphasis was on exercising and stretching. Within that period I was also fitted for my first brace: full brace on my right leg connected at the hip joint to a full back brace. I started out being kind of skinny, but with reduced activity I began to gain weight. That caused a problem with my ego since I had to shop in the *chubby girls* department and because the brace's hip joint had a nasty habit of chewing up my skin and clothes.

In June I was finally released to go home. My mother had sewn various weights of sandbags, from 1 pound up to 5 pounds. My father made an exercise board which I straddled lying down. This allowed me to work one leg at a time. We had a physical therapist come in to show us how to do the routine. Once ready, my father took over and worked with me.

So now I'm in 6th grade, having kept up with my class. Junior high continued on in much the same manner: school; exercises at home; twice-weekly trips to the hospital for more therapy; hanging out with the girls; and rarely mentioned but always present was the prospect of one year in bed following a spinal fusion. "In bed" meant flat on my back encased in a full body cast that held my head steady, stopped at the hip on one side, but the other leg had plaster down to the knee. All the stretching my father insisted on paid off. I was able to avoid a time consuming and uncomfortable process of straightening my spine before surgery so the "bone meal" would fuse some 13 vertebra in a straight line. The other advantage the suppleness gave me was that I could have a new cast after the fusion. The fusion was done in 2 stages and after the second stage I got a clean new cast.

My surgery was in November 1955. My home for the year was on a hospital bed in our dining room. My dad always came home for our main meal at noon. My sister came home from school for the meal. So now we ate together in the dining room – they at a card table and I ate propped up on my belly.

That was also the way I went to school. The district sent one teacher for English, Latin and math and a second teacher for science and social studies. Five mornings a week the student-teacher ratio was 1:1.

Friends came over often after school and my buddies and I swooned over Elvis Presley (much to my parents chagrin.) In July I had my last trip by ambulance to St. Charles Hospital to have my cast removed. What a wonderful feeling that was. No more cast. No more brace. My father still worked on strengthening my leg muscles and as I got used to walking without any aid, I got better at walking.

Once again I rejoined my class and had an active role in my school and my church's youth fellowship. After a year without activity it was great to be in the middle of things. Our high school was on double sessions so, in 10th grade I attended from 12:30 to 5:00 but in 11th grade I was through by noon and free in the afternoon. One of my best friends had the use of her

brother's old sedan and we would drive around looking for trouble and being glad we never found any. My senior year we were back to a regular schedule, but I had my own car and a blessed sense of freedom.

From 1963 until 2000 I would have to call my normal, active years. In college the only accommodations to my polio were the fact that I had a car my freshman year and a standing appointment with the college trainer for exercises and stretching. This meant I had to sit in line with all the jocks to wait my turn to work with the trainer.

College, marriage, employment, motherhood, a graduate degree; these all came in their appropriate time and I was blessed to be able to make the most of everything. I pushed myself to be active. My good husband, when he was running, would run twice around our block in the time it took me to walk it once. I graduated from driving an automatic with a hand operated brake and "a necker's knob" to driving a manual shift Z-car by 1975. I shoveled our driveway (Rochester NY gets about 93" a year); I painted the outside of our 2-story home (our niece helped); and I took my mother-in-law on our own tour around the world for seven weeks.

Never did I think being wheelchair bound loomed ahead of me. There were some early signs that something was happening. The first time I used a wheelchair as an adult was on Election Day 2000 at Epcot. We immediately found that there are some advantages to being in a wheelchair. We got into the line to enter our first building when an attendant pointed at Paul and said, "Come with me, young man." Paul thought "What have I done now?" but he put us at the head of the line, on to the ride, and took the chair away. When the ride was over, there was the chair waiting for us.

From 2000 until 2012, when I broke my leg, it has been a progression of increasing disability. I got to the point that, even with my walker, I walked bent over because my back muscles were too weak to hold me upright. Each of you has some acquaintance with this thing called PPS. I don't need to go through all the manifestations. I would like to share with you a recent awareness. The latest PPS bulletin from Boca Raton contained a comment by an author about his feeling of guilt. He wondered what he had done that God was punishing him this way. My thinking was different. I felt that God gave me the chance to carry the burden of polio for some other little girl who could not handle it as well as I.

Thank you for being good listeners.

My Polio Story

by Tom Schendorf



This might be the first time in my life I'm going to say that I don't have very much to say. I also really feel, looking around this room, that I have been very, very lucky. And I have not had nearly the problems that many of you had. I have problems I have to deal with, but not nearly what you have to deal with.

I was eight years old when I was told I had polio. I had been in bed for two weeks. Doctor came by; I had a fever. He said "I think it's polio." The fever broke; I got out of bed and basically went on with my life. I went to college, got a job, traveled a lot around the world, got married, had children. So basically I had a normal life and didn't even know about polio. I don't know exactly when I had it. I mean I don't know the dates. And I don't know the details that you all know. When I was fifty, I was walking around Tokyo, as I said on television one day with Janet (Tom and Janet DiClaudio appeared on

Mid-Morning Live on WTOG TV), and I was starting to have trouble. And I went to see doctors in Boston where we lived. And I'm sure you've all experienced this. There are more doctors than diagnoses and no solutions. The one thing that did happen to me in Boston was that I was put in touch with a fellow by the name of Ted Munsat at Tufts University. And he basically said I had either MS or post-polio. The reason I mention Ted Munsat's name is that a lot of you probably do work with a doctor here in town called Bodziner, Dr. (Richard) Bodziner. He trained at Tufts University with Dr. Munsat. Munsat was a very, very good doctor. There were no drugs. There are no pills. There's no solution. Basically I managed it through exercise and when it hurt, I'd take pain pills. I take Tramadol; I take about 250 milligrams of that a day. But that allows me to play golf with Harvey and beat his brains out and catch a hard time. So that kicked back in when I was 50, and they told me that it would gradually deteriorate. I was able to flatten that line out, but I still have what I would call a step-function down. About five years ago I took another step-function down. I can't travel- but I can travel, but what's the fun of sitting in a hotel room? Why waste the money? I can't play golf like I once used to, but maybe once or twice a month, Harvey and I will get out and make idiots of ourselves. And the final thing I can do is that I can still bitch and moan. I have not lost that capability. But let's be frank. I'm 75 years old. When I think of what's happened to some of my friends, not with polio necessarily, but with other diseases, I'm very, very fortunate. And I would assume that many of us are in the same position with things that have gone on with friends. And one of the big things- - one of the great things that has happened to me since I moved to Savannah is that I found the polio group and ways to deal with the polio. Probably more mentally than physically and I really appreciate that. I really feel that this organization fulfills a need for all of us.



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Shining Light on Post-Polio Health

Next Meeting
 Saturday,
May 17, 2014
 10:30 AM
 at Nancy N. and J.C. Lewis
 Cancer & Research Pavilion
 Room 203
 225 Candler Drive
 Savannah, GA

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 - \$20.00 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**
 P.O. Box 14252, Savannah, GA 31416.

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

Name of member

Thank you for your support and encouragement.