



THE LIGHTHOUSE

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

May, 2013 Newsletter

www.coastalempirepoliosurvivors.org

Vol. XVI, No. 5



The President's Message...

What a grand 16th anniversary celebration we had April 27!! We were delighted to welcome members, family, and friends to the event. Once again our hospitality committee—Terri & Michael Dunnermann and Adrienne & Ed Stallworth—did a fabulous job. Lavonne Calandra and Betty Goff assisted in getting our final count of attendees. The decorations, table settings, registration table, food, and cake were great. A big Thank You to all!

We were pleased to honor the Rotary Club of Skidaway and Belfor Savannah for the home modification completed for Lorraine Frew. Accepting plaques were Doug Powelson, president, and Tom McGoldrick, immediate past president, of Rotary and Jason King, general manager, of Belfor. Tom Schendorf and Harvey Varnedoe of CEPESA were thanked for their work on the project.

Dick Warden set the tone for the program with his inspiration. Our three speakers—Hattie Evensen, Harriett Merritt, and Barry Turner—brought smiles and tears to us as they described their polio journeys. We will remember many things from their talks. The common theme for me was their courage. When Hattie spoke, I was amazed to think of not only her courage, but that of her sister, who developed a disability just months prior to Hattie's getting polio, and her parents. Harriett overcame multiple challenges and came out on the other side, achieving a positive outlook and a good life when many would have lost hope. Barry shared his determination to achieve his dreams and have a successful life, not allowing others to limit his opportunities or tell him what he could not do. We salute the three of you and thank you for being in CEPESA.

Happy Mother's Day to all you CEPESA moms! Let us remember our polio mothers on that special day. Very few of us still have our mothers with us. I say a very special prayer of thanks on Mother's Day and every day for my beloved mother. She saw me through the darkest days of my polio journey and was there to share my greatest successes as well. Recently my sister Sheila told me that she thinks prayers were answered when I walked again within eight months of being discharged home with paralysis in both legs. My mother, grandmother, and three-year-old sister prayed for me every morning before they began my exercises. God Bless the strong women in our lives.

Cheryl Brackin, President

What's Inside THE LIGHTHOUSE:

CEPSA Business 2-3

- General Meeting Minutes
- April 27, 2013 Signees & President's Note
- CEPSA Anniversary Special Guests
- Upcoming Meeting Dates
- Updated CEPESA Brochures Available for Distribution

Photos 4-5

- CEPSA's Sweet16 Celebration

Polio Stories 6-8

- As Shared at our 16th Anniversary Celebration
- My Polio Story: Hattie Evensen
- My Polio Story: Harriett Merritt
- My Polio Story: Barry Turner

Library List 9

- Library of the Coastal Empire Polio Survivors Assoc., Inc.

Announcements 10-11

- Birthdays
- Member Concerns
- Memorial Day (Poem) In Your Honor
- Prayer Request
- Congratulations
- Mail
- Quote of the Month
- Mother's Day
- The Special Mother by Erma Bombeck

Articles 12-15

- Pioneering Polio Vaccine Developer Hilary Koprowski dead at 96.
- Advanced Directive for Health Care

FYI 15

- Funds Available to Polio Survivors
- CMS Procedure for Powered Mobility Devices

Contributions 16

- Contributions Form



Next Meeting
Saturday,
May 18, 2013
10:30 AM

Coastal Empire Polio Survivors Association, Inc.
16th Anniversary Celebration
April 27, 2013
Location: Marsh Auditorium

President Cheryl Brackin called the meeting to order at 10:46am, welcoming everyone. She introduced special guests Doug Powelson and Tom McGoldrick of the Rotary Club of Skidaway and Jason King of Belfor Savannah. She asked that members introduce their guests.

Lorraine Frew led the Pledge of Allegiance.

The inspiration was given by Dick Warden. He shared with us the definition of "Inspiration" and then explained how we are inspired in our own lives by our interaction with people. His personal inspiration came from his grandfather, stepfather and special friend Jamie, among others. We should all learn from others through our contacts with them.

The Rotary Club of Skidaway was recognized and thanked by Lorraine Frew for the bathroom modification project. Accepting a plaque of appreciation were Doug Powelson, President, & Tom McGoldrick, immediate past President. Tom Schendorf recognized and thanked Belfor Savannah for providing all the materials and labor for the project. Accepting a plaque of appreciation was Jason King, General Manager. Lorraine expressed her thanks for the home modification. Cheryl thanked Tom Schendorf and Harvey Varnadoe for their collaboration on the project.

Member concerns included Betty Goff and Janet DiClaudio. Cheryl read a letter from Janet that she thanks everyone for the cards, visits, and prayers for her continued healing. Quotes were read from a letter from a new member, Reverend Edna Love of Lafayette, Louisiana, who appreciates receiving our newsletter and information.

Financial Report: Marty Fox gave the financial report, which was approved as presented.

Program- Polio Stories: Cheryl introduced the three speakers: Hattie Evensen, Harriett Merritt and Barry Turner. Their stories are on pages 6-8 of this issue of the newsletter.

Announcements: Cheryl thanked Wanda & Carlos Clas for their designing our new brochures and holders. A signup sheet was placed on the registration table for members to sign up to obtain brochure kits at our May 18 meeting. We were asked to indicate where we will take the brochures, so we can prevent duplication. Wanda reminded us to first get permission to put out the holder with brochures and then be sure to refill them. We are trying to get the word out about PPS and the CEPASA support group. Cheryl reminded everyone that we will meet on May 18, the third Saturday in the month, due to the fourth Saturday falling on Memorial Day weekend.

The meeting was adjourned at 11:53 am.

Everyone was invited to enjoy the wonderful food and

decorations put out by Adrienne Stallworth and Terri Dunnermann with the assistance of Ed Stallworth and Michael Dunnermann. Lavonne Calandra and Betty Goff were thanked for assisting with the final count for the event. Our Hospitality Committee was praised for once again doing a great job.

Respectfully submitted,
Michael Dunnermann, Vice-President/Secretary

April 27, 2013 Guest Book Signees



Cheryl Brackin, Lorraine Frew, Susan Pineo, Paul Pineo, Archie Ivey, Sissy Morel, Barry Turner, Richard Graham, Linda Graham, Riley Metzger, Lily Higdon, Lavonne Calandra, Harriett Merritt, Dale Merritt, Lyn Meeks, Charlotte Richter, Larry Richter, Jim Veccia, Gigi Veccia, Fran Hodgkins, Joan Page, Alan Page, Richard Warden, Jamie Thompson, Marie McManus, Hattie Evensen, Robert Allen, Carlos Clas, Wanda Clas, Doug Powelson (Rotary Club of Skidaway), Tom McGoldrick (Rotary Club of Skidaway), Jason King (Belfor Savannah), Delores McIntyre, Tom Schendorf, Jan Schendorf, Brenda Mills, Terri Dunnermann, Michael Dunnermann, Adrienne Stallworth, Ed Stallworth, Diane Davis, Ruth Parham and family (Wakil, Kessha & David), Ann Chance, Della Simmons, Esther Simmons, Deno Caloudas, Marty Foxx & Dan Shehan.

Dear All,

We had another wonderful anniversary celebration today. Thanks to all of you for being there.

I appreciate all the efforts by board members to make the event a success (Betty and Harvey, we missed you.) Thanks to all for talking to the attendees and helping them feel welcome. Kudos again to our great hospitality team!! Tom Shendorf was right...the cake was sinful!

Cheryl Brackin, President



From an e-mail from Cheryl Brack. 27 April, 2013.

CEPSA Anniversary *Special Guests*



CEPSA founder Lorraine Frew presented a plaque to Doug Powelson, president of the Rotary Club of Skidaway, as Tom McGoldrick, immediate past president, looked on.



Tom Schendorf (L), presented a plaque to Jason King, general manager of Belfor Savannah, as Lorraine Frew looked on.



(L to R) CEPSA member Tom Schendorf, Tom McGoldrick, 2011-2012 president of the Rotary Club of Skidaway and Jason King, general manager of Belfor Savannah.



Our special guests before the presentation of plaques at the Marsh Auditorium on April 27, 2013 with Tom Schendorf (center, left), who along with Harvey Varnadoe (not shown), spearheaded the Home Modification Project.

Upcoming Meeting Dates

May 18, 2013 @ Exchange Restaurant
June 22, 2013 @ Exchange Restaurant

Updated CEPSA Brochures Available for Distribution



The updated CEPSA brochures have been printed and placed into brochure holders that are available now for distribution. Each holder will contain 25 brochures and instructions for our members to take to their doctors, therapists, hospitals, medical facilities, etc. that will allow us to display them. If you are interested in taking one, please see Cheryl Brackin. Cheryl will write down your name and where you will be taking the brochures for display. You will be responsible for maintaining the holders by checking them on occasion and refilling them if necessary. The holders will have the CEPSA information on labels on the inside and outside to insure that you recognize them in case they are empty when you visit the facility where you placed them. Please...you **MUST** ask permission to display the holders. **DO NOT** assume that it is okay to leave them in the facility, office or waiting room. We don't want them thrown out because we didn't get permission to display them. When you get permission, take down the person's name and position for future reference. This is a great way for members to "help" get the word out on polio, Post-Polio and CEPSA.

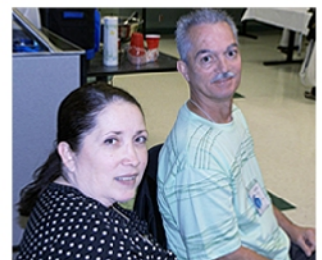
Voluntary Dues of \$15.00 may be paid to Marty Foxx.

CEPSA's Sweet 16 Celebration April 27, 2013



Photos Courtesy of Charlotte Richter, Larry Richter, Michael Dunnermann & Jan Scendorf

CEPSA's *Sweet 16* Celebration April 27, 2013



Photos Courtesy of Charlotte Richter, Larry Richter, Michael Dunnermann & Jan Scendorf

My Polio Story

by Hattie Alene Wilson Evensen
Born: October 7, 1952



My polio story begins with my family, especially Mom, and what faith, strength and determination can do in your life.

Since I was so young, age 4, I have NO memories of the onset of polio. I have very little memories of my childhood. I think I have mentally blocked out the entire experience.

My story begins with my sister, Dale; she is three years older than me. In May 1956, at age 6, she developed measles and was diagnosed with Encephalitis which left her brain damaged. Within two months, several doctors from Waycross, Georgia saw her and basically gave up on her, stating they could not do anything else for her.

Daddy took Dale home in July, still unconscious. Her feet, hands and arms were drawn up and she had a feeding tube in her nose down to her stomach. After a week at home, my parents took her to Jacksonville, again doctors gave no hope!! My parents were not going to give up on her!! Through determination, Mom trained Dale to swallow enough milk and soft food to keep her alive. She gradually began to get better, and the doctor took the tube out of her nose. She was like a newborn baby and had to be taught to talk, walk and feed herself all over again.

But the story goes on. In December 1956, I got sick with a fever and flu-like symptoms. I woke up, called out to Dad to come get me because I could not walk. Daddy told me I could walk and for me to get up and come in their room. I got

out of bed struggling to walk but just as I made it to their bed; I fell and never walked again without assistance.

My parents took me to the doctor in Waycross. I was admitted to the hospital with a kidney infection. During my 31 days in the Waycross Hospital, they performed all sorts of tests and they performed a spinal tap. On December 18, 1956, I was diagnosed with paralytic polio. Specialty doctors from the Medical College of Georgia in Augusta came down to the Crippled Children's Clinic in Savannah and Waycross to see patients. Dale and I were treated at this clinic until we reached 19 years of age.

The doctors put me in a full body corset brace with long double upright braces, (under both arms all the way down to my feet.) They also taught Mom to tie three pound weights on both of my legs and perform exercises every night. (This I remember, because I hated it).

In August 1957, I was sent to Emory University to learn to walk with my crutches. During the five weeks at Emory doctors removed the body brace, but I had to continue using both long leg braces and crutches. In October 1959 and November 1961 I had two series of operations on my legs, hip, and heel. Doctors said my chances of ever going without even one brace was slim and I would always have to wear one on my right leg. Well, I proved them wrong. I use one long leg brace and one short leg brace. I have not been under a doctor's care for my polio until recently.

Now with the onset of Post Polio-Syndrome, the second part of my story is beginning to change and only God knows what path life will take. I pray I have the faith, strength, and determination my Mom has and continues to have in her life.

When I get downhearted, I always think about the circumstances my parents must have experienced in dealing with two such different handicapped children beginning all in same year. This has influenced my life to always have faith, and in time with determination, you can conquer whatever life brings your way. Never Give Up.

My Polio Story

by Harriett M. Merritt
Born: January 14, 1942



Let's start with 71 years ago and fast-forward through the years. January 14, 1942, I was born Harriett Mae Schneider. I was the 9th child, of which 6 died shortly after birth.

In June, 1942, I came down with a very high temperature of 103.5 and was rushed to Janesville, Wisconsin, about 30 to 35 miles away, to a Catholic hospital where my mother was told I had polio. They were not sure they could save me. My father was in the army and was called home. Because of all the medical care I would need, I was placed a ward of the courts and would not return to the Schneider household again.

I lived at the Catholic hospital for two years and 3 months. There were two very special Sisters there: Sister Agathon and Sister Vanaronda. I couldn't say Sister Vanaronda's name, so I called her "Sister Run-around." Then there was Dr. Clark. I waited at the elevator each day and said "candy, candy," because he always had candy in his suit coat pocket for me.

It was on Good Friday, March, 1944, that I was placed in a foster home, where I now had a mother, father, two sisters and a brother. Because of all the medical bills I could not be adopted and would stay a ward of the courts. My foster father and youngest sister would be with me through all of my hospital stays. My sister would come along because it was about a 45-mile drive. My father would cry on the way home because he couldn't bring me back with him. This went on from the time I went into that family until November 11, 1948, when my father died. My sister and brother then took over as parents to me. I was only 6 1/2 when my father died. I can remember when the man from surgery would come to take me, and he would say, "Now kiss your mommy goodbye." I would say, "She is my sister, not my mother."

In 1950 during the 23rd surgery on my left leg, they ended up amputating my leg at the ankle because it wouldn't grow. They kept adding to the lift on my leg brace over the years, and it would put my back out. We were told,

without this surgery, I would be in a wheelchair the rest of my life. I was 8 years old at the time. After a year at the hospital, off and on, and mostly on, I was taken home. My foster mother would call people in off the street to have me take off the prosthesis to see my leg. For a long time I couldn't or wouldn't take the leg off with others around, or even talk about it.

Skipping ahead a few more years to about the 7th or 8th grade, my school had roller skating parties one or two times a month. My mother would say, "NO, NO, you can't do things like that!" I had a very special principal who talked her into letting me go along, but she said "no skating." I was able to get up on skates with the help of one of the parents. I even won a roller skating contest!

As the years went on, I was told of more and more things I couldn't do because I was handicapped. In high school I was in two plays, sang in the choir, and was in the Civil Air Patrol talking about flying. I even started for my license!

At 22 years old I was still told I couldn't drive. Well, I do drive. My first big trip was to Ft. Worth, Texas, from Wisconsin, by myself, to be with my first husband. He also would say there were things I couldn't do and would keep bringing up the fact that I was handicapped.

On March 31, 1984, I married Dale R. Merritt, had eight lovely step-children and was truly happy to be able to start life over again. We do everything together and enjoy life. He doesn't look at me as a handicapped person. I'm his equal.

On December 2, 1993, I had another setback. I fell while shopping in Savannah. When the doctor came in the ER and told me his name, I asked him if he had a brother in Barnwell because if he didn't perform the surgery right I would be going to visit him...he is my lawyer! I shattered the bones in my left leg, and we were told I may lose the leg at the hip, but I lucked out, and the doctor fixed it up. I was in a wheelchair for 2 1/2 years and didn't know if I would ever walk again. The doctor said if I did walk again, I could use a walker or something. But with all the support of my family and friends in Hardeeville, I was up and walking again, with a walker for a while, but still not like I used to walk.

Oh, yes, I have good and bad days, but we all do, and you can work through them.

I'm so glad I found my husband and new family and a new start in life. Now I have found more friends in the Coastal Empire Polio Survivors Association, and I have wonderful friends like you all are. We all have the same goal in life, and that is to survive something we never asked for, and that is polio. We will make it with the support of each other, our families, our friends, and knowing our goals in life and to keep working each day towards those goals.

My Polio Story

by Barry D. Turner

Born: March 2, 1951



I got polio in 1953 at the age of 2. I can remember going to Warm Springs, GA. From 1953-1957 I lived in Los Angeles, California. I used to walk on my toes on the right foot for balance. After returning to Savannah in 1957, I had the first of 16 operations on my right leg in 1958, and several surgeries throughout the 1960's. The last one was in 1967.

My brothers went to Bethesda Home for Boys in 1958. Bethesda would not take me because I had polio, so I stayed home with mom.

In 1959 my brothers came home from Bethesda and in 1960 mom passed away. I went back to Bethesda, and this time I was allowed to stay. It worked out. I dealt with bullying from the older boys, but not for long, I started lifting weights and took care of the bullying problem!

I had a disc jockey job at night from 1969-1972, midnight to 7 am. I disc jockeyed at night and went to school during the day, while still in high school and also managed a band.

The first time I had issues with polio was when I decided to get a degree in Equine Science. My school in Maryland talked to the manager of a breeding farm about attending their program. They had eight students, and he gave me an available slot on the 3000-acre farm that had 300 horses. I did not tell him about my polio on the phone; he didn't ask so I didn't tell. About 2 weeks after arriving at the farm, the manager wanted to talk to me about my polio. He ask why I did not tell him about having polio and I told

him I was afraid he would not allow me the opportunity to prove myself. He said "You're probably right," and he told me I could not train and compete in show rings because you have to use your legs to cue the horse. I said I did not want to be a trainer and that I was there for his job. He was confused. I explained to him that I wanted to learn all I could about the horses and running a large farm like this. He was very pleased, and I was in very good standing from that point on.

There had been 225 students at the start of the program, and I was only the 25th person to complete and graduate the program. All the others quit because it was such hard work.

In 1975 I had polio issues and again was given a chance, this time by the City of Savannah. I worked for the City Of Savannah from 1975-2006, and I retired after 29 years.

One word I dislike is *handicap*. It is a mental and negative word. I also do not like the word *can't*. It is acceptable, however, if I use it on myself because it is acknowledging limits to myself. When someone else says "You *can't* do something," that is prejudging my limits...if any.

We have polio, polio does not have us!



Horse! God's way of giving freedom.

<http://pinterest.com/profchoice/equine-inspiration/>.

To check out books or videos from CEPESA's Library,
 e-mail Diane Davis at davi1192@bellsouth.net or sign the Library Check-out Sheet
 at a General Meeting and Diane will bring your selection to the following meeting.



Library of Coastal Empire Polio Survivors Association, Inc.

Books

Books

Books

- **The Polio Paradox**
by Richard L. Bruno H.D., Ph.D., 2002
- **Roosevelt —The Soldier of Freedom**
by James MacGregor Burns
- **The End of Polio —
A Global Effort to End a Disease**
by Siddharth Dube and Sebastiao Salgado,
Photographer
- **The Roosevelts —An American Saga**
by Peter Collier 1994
- **In The Shadow of Polio —
A Personal and Social History**
by Kathryn Black 1996
- **Managing Post-Polio —A Guide to
Living Well with Post-Polio Syndrome**
by Lauro S. Halstead, MD 1st Edition
- **Managing Post-Polio —A Guide to
Living Well with Post-Polio Syndrome**
by Lauro S. Halstead, MD 2nd Edition
- **Handbook on the Late Effects of
Poliomyelitis for Physicians and Survivors**
Edited by Frederick Maynard, MD and Joan L.
Hendley, MS (Revised 1999 edition)
- **Dancing with Katya**
by Dori Chaconas —Illustrated by Constance
Bergum (Children's Book)
- **Living with Polio —
The Epidemic and Its Survivors**
by Daniel J. Wilson
- **Life Without Limits —Inspiration for
a Ridiculously Good Life**
by Nick Vujicic

DVDs

DVDs

DVDs

- **The Last Child —
The Global Race to End Polio**
Director/Producer: Scott Thigpen
(4 Copies)
- **A Paralyzing Fear —
The Story of Polio in America**
by Nina Gilden Seavey
- **The Final Inch —In the fight to eliminate polio,
the last step is the biggest.**
Vermillion Pictures
- **A Fight to the Finish —Stories of Polio**
- **Modern Marvels:
In Search of the Polio Vaccine**
(1997) 50 Minutes
- **Breathing Lessons —
The Life and Work of Mark O' Brien**
- **Safe at Home —Planning for Independence
Through Home Modifications**
Narrated by Bob Vila
- **Aquatic Therapy for Polio Survivors**
by Rothhammer International, Inc.
Series 2 (1997)
- **"Warm Springs"**
with Kenneth Branagh as FDR and
Cynthia Nixon as Eleanor
(120 Minutes)
- **FDR —A Presidency Revealed**
(2 DVD's Part 1 & 2)
- **Post-Polio Health International Conference —
September 24, 2005**
(3 DVD's Part 1, 2 & 3)

Many thanks to Diane Davis for maintaining and overseeing the CEPESA Library and
 to Carlos and Wanda Clas for transferring CEPESA's video library from VHS tapes to DVDs.



Happy Birthday

May

Bob Parkhurst - 6
 Lucille Robinson - 13
 Esther Simmons - 13
 Vivian O'Kelley - 14
 Allen Igou - 17
 Wanda Clas - 19
 Jan Schendorf - 19
 Dale Merritt - 26
 Richard Graham - 31

June

Delores McIntyre - 10
 Harriett Merritt - 10
 Brenda Mills - 10
 Ed Stallworth - 12
 Marie McManus - 13
 Charles Orr - 14
 Ruth Parham - 14
 Janet DiClaudio - 17
 Harvey Varnadoe - 22
 Steve Hess - 28

Member Concerns

Janet DiClaudio, Betty Goff & Penny Smith

Please keep these members in your prayers.



Memorial Day

May 27, 2013

Don't Forget to Remember.

In Your Honor

Unselfishly, you left your fathers and your mothers,
 You left behind your sisters and your brothers.
 Leaving your beloved children and wives,
 You put on hold, your dreams-your lives.
 On foreign soil, you found yourself planted
 To fight for those whose freedom you granted.
 Without your sacrifice, their cause would be lost
 But you carried onward, no matter the cost.

Many horrors you had endured and seen.
 Many faces had haunted your dreams.
 You cheered as your enemies littered the ground;
 You cried as your brothers fell all around.

When it was over, you all came back home,
 Some were left with memories to face all alone;
 Some found themselves in the company of friends
 As their crosses cast shadows across the land.

Those who survived were forever scarred
 Emotionally, physically, permanently marred.

Those who did not now sleep eternally
 'Neath the ground they had given their lives to keep free.

With a hand upon my heart, I feel the pride and respect;
 my reverence is revealed

In the tears that now stream down my upturned face
 As our flag waves above you, in her glory and grace.

Freedom was the gift that you unselfishly gave
 Pain and death was the price that you ultimately paid.

Every day, I give my utmost admiration
 To those who had fought to defend our nation.

~ Author Unknown ~

Prayer Request

Lorraine Frew is asking for your prayers for CEPESA member Richard Hall's niece, Brenda. We wish her a complete and speedy recovery.

Request received via telephone from Lorraine Frew . 22 April, 2013.

Congratulations

Congratulations to Dr. Anne Thompson, Associate Professor and Department Head of Physical Therapy at Armstrong Atlantic State University, on receiving an Award for Distinguished Faculty Service to the University. Dr. Thompson is a friend of CEPESA and is very knowledgeable about the late effects of polio. She has spoken twice to our group. We wish her continued success in her work.

From an e-mail from Cheryl Brackin to Carlos & Wanda Clas . 22 April, 2013.



Congratulations to Delores McIntyre on the birth of her great grandson, Nathan Osbourne Tindall. The world welcomed Nathan on April 25, 2013. He weighed in at 7 lbs. 9 oz. and was 21.5" long at birth.

CEPSA would like to congratulate Esther Simmons who was chosen by her church to represent them in Washington, D.C. on May 25th. All the best for a safe trip!

Mail

Dear Cheryl,

My doctor has told me that I am doing great. She is very pleased with my progress and so am I. I hope you can read this.

Other than my health care, I truly believe that my progress is due to the great support from CEPESA...cards, visitors and many prayers.

Please thank everyone for me. I am planning on getting to go home and hopefully attend a CEPESA meeting in a few months.

Thanks Again.

Love,

Janet DiClaudio

From a note to Cheryl Brackin from Janet DiClaudio . 13 April, 2013.

Dear Ms. Brackin,

Thank you for sending the packet of post-polio information. I appreciate it very much. I am amazed at the organization you have in the CEPESA Association. Someone has done a lot of footwork to have such a wonderful community established. I so wish that someone in this area had done the same. I have considered trying to get something started, but with dealing with my own post-polio, which has been progressing at a rather alarming rate, plus trying to care for my 83 year old husband, who has Alzheimer's, I have little time or strength to tackle such a project. In better times, I would not have hesitated a minute to do so. It's difficult to acknowledge our limitations, and then to abide by them!

I particularly appreciated the little card with the instructions for the health care providers concerning anesthesia at times of surgery. Although I have in the past tried to inform the anesthesiologists of the special needs, the doctors paid little attention, thus there have been several negative experiences. How delighted I was last month when I had my first cataract surgery, to discover the delightful young anesthesiologist who was caring for me, had received her schooling in Houston where she had received extensive training in this field. The surgery was successful and there were no after affects of the anesthesia, which only lasted a short time. This Tuesday I will have the second eye done, so I am praying for another good experience.

I wish you and the whole of the CEPESA group the very best, and may God bless you as you expend the effort to make the world a little easier for all polio survivors, and as you strive to inform the general public concerning Post-Polio.

Sincerely,
Edna Love
Rev. Edna Love, Ret.

From an e-mail to Jim Vecchia from Cheryl Brackin . 19 April, 2013.

Dear Editors,

As I look at each newsletter, I think it couldn't get much better than this and up pops another great newsletter. The content is very useful and I have passed info. along to some of my friends.

Thanks for a great job.
Delores McIntyre

Dear Delores,

Thank you so much for always having such kind remarks about our efforts, sharing your newsletter with your friends and forwarding other group's newsletters and articles to us. They give us ideas about what we might include in future CEPESA newsletters.

Carlos & Wanda Clas, Co-Editors

From an e-mail to Carlos & Wanda Clas from Delores McIntyre. 13 April, 2013.

Happy Mother's Day – May 12, 2013

Quote of the Month

*I cannot forget my mother. She is my bridge.
When I needed to get across, she steadied herself
long enough for me to run across safely.*
- Renita Weems



Mother's Day is a holiday honoring motherhood that is observed in different forms throughout the world. The American incarnation of Mother's Day was created by Anna Jarvis in 1908 and became an official U.S. holiday in 1914. Jarvis would later denounce the holiday's commercialization and spent the latter part of her life trying to remove it from the calendar. While dates and celebrations vary, Mother's Day most commonly falls on the second Sunday in May and traditionally involves presenting mothers with flowers, cards and other gifts.

"Mother's Day." 2013. *The History Channel website*. Apr 26 2013, 3:29
<http://www.history.com/topics/mothers-day>.



The Special Mother by Erma Bombeck

This column was published
on May 11, 1980.

Most women become mothers by accident, some by choice, a few by social pressures and a couple by habit.

This year nearly 100,000 women will become mothers of handicapped children. Did you ever wonder how mothers of handicapped children are chosen?

Somehow I visualize God hovering over earth selecting his instruments for propagation with great care and deliberation. As He observes, He instructs His angels to make notes in a giant ledger.

"Armstrong, Beth; son. Patron saint...give her Gerard. He's used to profanity."

"Forrest, Marjorie; daughter. Patron saint, Cecelia."

"Rutledge, Carrie; twins. Patron saint, Matthew."

Finally He passes a name to an angel and smiles, "Give her a handicapped child."

The angel is curious. "Why this one God? She's so happy."

"Exactly," smiles God, "Could I give a handicapped child to a mother who does not know laughter? That would be cruel."

"But has she patience?" asks the angel.

"I don't want her to have too much patience or she will drown in a sea of self-pity and despair. Once the shock and resentment wears off, she'll handle it."

"I watched her today. She has that feeling of self and independence that is so rare and so necessary in a mother. You see, the child I'm going to give her has her own world. She has to make her live in her world and that's not going to be easy."

"But, Lord, I don't think she even believes in you." God smiles, "No matter, I can fix that. This one is perfect - she has just enough selfishness." The angel gasps - "selfishness? is that a virtue?"

God nods. "If she can't separate herself from the child occasionally, she'll never survive. Yes, here is a woman whom I will bless with a child less than perfect. She doesn't realize it yet, but she is to be envied. She will never take for granted a 'spoken word'." She will never consider a "step" ordinary. When her child says 'Momma' for the first time, she will be present at a miracle, and will know it!"

"I will permit her to see clearly the things I see...ignorance, cruelty, prejudice...and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life, because she is doing My work as surely as if she is here by My side".

"And what about her Patron saint?" asks the angel, his pen poised in mid-air.

God smiles, "A mirror will suffice."



Pioneering Polio Vaccine Developer Hilary Koprowski dead at 96.

Born in Warsaw, Poland, to a family of Jewish background, [1] Hilary Koprowski attended Mikotaj Rej Secondary School and from age twelve took piano lessons at the Warsaw Conservatory. He received a medical degree from the Faculty of Medicine at Warsaw University in 1939. He also received music degrees from the Warsaw Conservatory and, in 1940, from the Santa Cecilia Conservatory in Rome. He adopted scientific research as his life's work, though he never gave up music and composed several musical works.

In 1939, after the Nazi invasion of Poland, Koprowski and his wife Irena, a physician, fled Poland, using Koprowski family business connections in Manchester, England. Hilary went to Rome, where he spent a year studying piano at the Santa Cecilia Conservatory. Meanwhile Irena went to France, where she gave birth to their first child, Claude Koprowski, and worked as an attending physician at an insane asylum.[2] As the invasion of France loomed in 1940, Irena and the infant escaped from France via Spain and Portugal (where the Koprowski family reunited), to Brazil, where Koprowski worked in Rio de Janeiro for the Rockefeller Foundation. His field of research for several years was finding a live-virus vaccine against yellow fever.

After World War II the Koprowskis settled in Pearl River, New York, where Koprowski was hired as a researcher for Lederle Laboratories, the pharmaceutical division of American Cyanamid. Here he began his polio experiments, which ultimately led to the creation of the first oral polio vaccine. Due to his employment in the pharmaceutical industry, some of his academic colleagues called him a "commercial scientist."

Koprowski had married Irena (Grasberg) in July 1938, while in medical school.[3] They are survived by two sons, Claude (born in Paris, 1940) and Christopher (born 1951). Claude Koprowski is a retired physician. Christopher Koprowski is a physician certified in two specialties: neurology, and radio-oncology; he is chair of the department of radiation oncology at Christiana Hospital in Delaware.[4]

Koprowski served as director of The Wistar Institute, 1957-91, during which period Wistar achieved international recognition for its vaccine research and

became a National Cancer Institute Cancer Center.

While at The Wistar Institute, Koprowski created the world's first polio vaccine, based on oral administration of attenuated polio virus. In researching a potential polio vaccine, he had focused on live viruses that were attenuated (rendered non-virulent) rather than on killed viruses (the latter became the basis for the injected vaccine that was subsequently created by Jonas Salk).

Koprowski viewed the live vaccine as more powerful, since it entered the intestinal tract directly and could provide lifelong immunity, whereas the Salk vaccine required booster shots. Also, administering a vaccine by mouth is easy, whereas an injection requires medical facilities and is more expensive.

Koprowski developed the polio vaccine by attenuating the virus in brain cells of the cotton rat (*Sigmodon hispidus*), a New World species susceptible to polio.[6] He administered the vaccine to himself in January of 1948 and to 20 children at Letchworth Village, a home for mentally disabled children in Rockland County, N.Y., on February 27, 1950. Seventeen of the 20 children developed antibodies to poliovirus (the other three apparently already had antibodies) and none of the children developed complications. Within 10 years it was being used on four continents. Albert Sabin's attenuated-live-virus polio vaccine was developed from attenuated polio virus that Sabin had received from Koprowski.

Koprowski was President of Biotechnology Foundation Laboratories, Inc., and Head of the Center for Neurovirology at Thomas Jefferson University. In 2006 he was awarded a record 50th grant from the National Institutes of Health.

He is the author or co-author of over 875 scientific papers and was co-editor of several journals. He served as a consultant to the World Health Organization and the Pan American Health Organization.

Koprowski died on April 11, 2013 in Philadelphia of pneumonia. He was 96.[5]

Topic suggestion from an e-mail from Jim Vecchia. 14 April, 2013.

[<http://en.wikipedia.org/wiki/Hilary_Koprowski#cite_ref-1>](http://en.wikipedia.org/wiki/Hilary_Koprowski#cite_ref-1).

Notes

- [1] [David Oshinsky, *Polio: An American Story*, Oxford University Press, 2005, ISBN 0-19-515294-8.](#)
- [2] [Koprowska, Irena \(1997\). *A Woman Wanders Through Life and Science*. State University of New York Press. ISBN 9780791431771.](#)
- [3] http://www.nlm.nih.gov/changingthefaceofmedicine/physicians/biography_187.
- [4] <http://www.christianacare.org/body.cfm?id=961>
- [5] [Hilary Koprowski, polio vaccine pioneer, dead at 96 - Philadelphia Inquirer](#), April 13, 2013.
- [6] [Hilary Koprowski, Who Developed First Live-Virus Polio Vaccine, Dies at 96 - The New York Times](#), April 20, 2013.



(Please note that the following is information from the State Bar of Georgia. Check your State Bar for information outside of Georgia. In **SOUTH CAROLINA**, visit: <http://www.sbar.org/PublicServices/LawLine/AdvanceCarePlanning.aspx>.)

Foreword

You have the right to control all aspects of your personal care and medical treatment, including the right to insist upon medical treatment or direct that medical treatment be withheld or withdrawn. If you cannot (or do not want to) communicate your health care decisions for yourself, you have the right to choose someone to make health care decisions for you. You also have the right to state your treatment preferences if you have a terminal condition or are in a state of permanent unconsciousness.

The Georgia Advance Directive for Health Care Act gives you an opportunity to choose someone to make health care decisions on your behalf and to make a clear expression of your decisions regarding health care if you are in a terminal condition or state of permanent unconsciousness by executing an advance directive for health care.

What is an advance directive for health care?

An advance directive for health care (ADHC) is a legal document in which you (1) appoint your health care agent, and/or (2) direct the withholding or withdrawal of life-sustaining procedures and/or the provision of nourishment or hydration if you are in a terminal condition or a state of permanent unconsciousness. (Since 2007, the ADHC has replaced the legal documents called durable power of attorney for health care and living will in Georgia.)

Is any particular form of ADHC required?

You may use any form of ADHC that complies with Georgia law. However, the law provides a standard form of ADHC that will be treated as complying with Georgia law if it is properly executed. An attorney can provide you a form of ADHC and help you understand it, complete it and properly execute it. An ADHC must be in writing, signed by you, and attested and signed by two adult witnesses. You may revoke or amend your ADHC at any time.

Who may execute an ADHC?

Any adult who is of sound mind may execute an ADHC.

What is a health care agent?

A health care agent is a person appointed by you in an ADHC to act on your behalf to make decisions related to the consent to, refusal of or withdrawal of any type of health

care. A health care agent may also be given the authority to make decisions related to autopsy, anatomical gifts and the final disposition of your body after your death. A physician or health care provider who is directly involved in your care may not be your health care agent.

What is meant by health care?

Health care means any care, treatment, service or procedure to maintain, diagnose, treat or provide for your physical or mental health or personal care.

What powers does my health care agent have?

Your health care agent will make health care decisions for you only when you are unable to communicate your health care decisions or you choose to have your health care agent communicate your health care decisions. Your health care agent will have the same authority to make any health care decision that you could make. The health care agent's authority includes the power to admit you to or discharge you from any hospital, skilled nursing facility, hospice or other health care facility or service; the power to request, consent to, withhold or withdraw any kind of health care; and the power to contract for any health care facility or service for you and to obligate you to make arrangements for these services. Your health care agent may accompany you in an ambulance and may visit or consult with you in person while you are in a hospital, skilled nursing facility, hospice or other health care facility. If you choose, your health care agent will also have the power to authorize an autopsy of your body after your death, make a disposition of all or any part of your body for medical purposes and make decisions about the final disposition of your body.

Does my health care agent have access to medical records?

Your health care agent will be your personal representative for all purposes of federal or state laws relating to privacy of medical records and will have the same access to your medical records that you have and can disclose the contents of your medical records to others for your ongoing health care.

How does my health care agent make decisions?

When making health care decisions for you, your health care agent should think about what action would be consistent with past conversations the two of you have had, your treatment preferences as expressed in your ADHC, your religious and other beliefs and values and how you have handled medical and other important issues in the past. If what you would decide is still unclear, then your health care agent should make decisions for you that your agent believes are in your best interest, considering the benefits, burdens and risks of your current circumstances and treatment options.

Am I required to appoint a health care agent in

my ADHC?

You are not required to appoint a health care agent in an ADHC. If you wish, you may use an ADHC only to express your treatment preferences if you have a terminal condition or are in a state of permanent unconsciousness.

How do I express my treatment preferences for a terminal condition or state of permanent unconsciousness in my ADHC?

In an ADHC you may express your treatment preferences for either or both of two conditions: if you are in a terminal condition or if you are in a state of permanent unconsciousness. Your condition will be determined in writing by your attending physician and a second physician in accordance with currently accepted medical standards. Your treatment preferences in your ADHC will be followed only if you can no longer communicate your treatment preferences after appropriate efforts have been made to communicate with you about your treatment preferences. Treatment preferences are your decisions as to the withholding or withdrawal of life-sustaining procedures and/or the provision of nourishment and hydration (nutrition and fluids).

What is a terminal condition?

A terminal condition is an incurable or irreversible condition which would result in your death in a relatively short period of time.

What is a state of permanent unconsciousness?

A state of permanent unconsciousness is an incurable or irreversible condition in which you are not aware of yourself or your environment and in which you show no behavioral response to your environment.

What are life-sustaining procedures?

Life-sustaining procedures are medications, machines or other medical procedures which, when applied to you in a terminal condition or state of permanent unconsciousness, could in reasonable medical judgment keep you alive but cannot cure you and where, in the judgment of the attending physician and a second physician, your death will occur without such procedures or interventions. Life-sustaining procedures do not include administration of medication to alleviate pain or the performance of any medical procedures deemed necessary to alleviate pain. Life-sustaining procedures also do not include the provision of nourishment or hydration (nutrition and fluids), but you may direct the withholding or withdrawal of nourishment or hydration in an ADHC.

What are my options for treatment preferences for a terminal condition or state of permanent unconsciousness?

The form of ADHC provided by the law allows you to

express any one of three preferences for treatment if you are in a terminal condition or state of permanent unconsciousness: (1) Try to extend your life as much as possible, using all life-sustaining procedures, and if you are unable to receive nourishment or hydration (nutrition and fluids) by mouth, then you want to receive artificial nourishment or hydration (by tube or other medical means); (2) Allow your natural death to occur; you do not want any life-sustaining procedures or artificial nourishment or hydration; (3) You do not want any life-sustaining procedures except as you specifically indicate in the form, and you can choose to receive artificial nourishment and/or hydration, a ventilator and/or CPR. No matter which of the three options you choose, you may also provide additional treatment preferences on the form.

Can my health care agent make decisions regarding my treatment in a terminal condition or state of permanent unconsciousness?

Unless you provide otherwise in your ADHC, the treatment preferences expressed in your ADHC are ineffective so long as you have a health care agent who is available and willing to make decisions on your behalf regarding the withholding or withdrawal of life-sustaining procedures and/or the provision of nourishment or hydration. However, your health care agent is required to take any treatment preferences expressed in your ADHC into account when making decisions about your health care.

Am I required to express my treatment preferences for a terminal condition or state of permanent unconsciousness in my ADHC?

You are not required to express treatment preferences for a terminal condition or state of permanent unconsciousness in an ADHC. If you wish, you may use an ADHC only to appoint a health care agent.

Is my health care provider required to honor my ADHC?

If your health care provider receives your ADHC, your health care provider has the responsibility to enter the ADHC in your medical records, to grant your health care agent adequate access to you, to consult with your health care agent, to comply with the decisions of your health care agent and to give your health care agent the same right to examine and copy your medical records that you would have. A health care provider who fails or refuses to comply with your treatment preferences regarding the withholding or withdrawal of life-sustaining procedures and/or the provision of nourishment or hydration must advise your health care agent (if you have one) or your next of kin or guardian and, if directed to do so, must allow you to be transferred to another physician who will comply with your treatment preferences.

What effect does my marriage or divorce have on my ADHC?

Unless you provide otherwise in your ADHC, if you get married after executing an ADHC, the marriage revokes the designation of anyone other than your spouse as your health care agent. And unless you provide otherwise in your ADHC, if you get divorced after executing an ADHC, the divorce revokes the designation of your former spouse as your health care agent.

What is the difference between an ADHC and a durable power of attorney for health care?

Georgia law used to provide for the appointment of a health care agent in a document called a durable power of attorney for health care. Since 2007, the ADHC has replaced the durable power of attorney for health care in Georgia. Your durable power of attorney for health care executed under the old law remains effective, but it would be a good idea for you to replace it with an ADHC.

What is the difference between an ADHC and a living will?

Georgia law used to provide for the declaration of treatment preferences for a terminal condition and state of permanent unconsciousness in a document called a living will. Since 2007, the ADHC has replaced the living will in Georgia. Your living will executed under the old law remains effective, but it would be a good idea for you to replace it with an ADHC.

What is a guardian?

A court will appoint a guardian for you if the court finds that you are not able to make significant responsible decisions for yourself regarding your personal support, safety or welfare. A court will appoint the person nominated by you if the court finds that the appointment will serve your best interest and welfare. In an ADHC, you may nominate a person to serve as your guardian in the event a court decides that a guardian should be appointed. You may (but are not required to) nominate your health care agent to be your guardian. A guardian does not have the power to manage your property or financial affairs.

This pamphlet was prepared by the Fiduciary Law Section of the State Bar of Georgia as a public service. It is not intended to be a comprehensive statement of law. Its purpose is to inform, not to advise on any specific legal problem. If you have specific questions regarding any matter contained in this pamphlet, you are encouraged to consult an attorney.

Thank you to Sarah Coole, State Bar of Georgia Director of Communications for giving us written permission to reprint. She said that they may change the content or update the information on their site without notification. Please check their website often for updated information.

<<http://www.gabar.org/newsandpublications/consumerpamphlets/Advance-Directive-for-Health-Care.cfm>>.

For a FREE COPY of YOUR STATE'S
Advance Directives FORM, visit:

<<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>>.

This information was provided in response to a suggestion from Cheryl Brackin.

FYI



Funds Available to Polio Survivors

Maximum Increased: The Joyce and Arthur Siegfried Memorial Fund and the Gilbert Goldenhersh Memorial Tribute Fund (Missouri residents only) have funds available to assist survivors in need to purchase bracing, or modified/custom-made shoes. The maximum amount available per person has been increased from \$500 to \$800. It is easy for one of your members to obtain an application and an explanation of the process, just email info@post-polio.org or call 314-534-0475.

For more information go to www.post-polio.org.

Information and link provided by Jim Veccia via e-mail. 15 April, 2013.

So much corruption abounds on disabled persons and as a result we will eventually suffer!!!!

-Jim Veccia

CMS Procedure for Powered Mobility Devices



You may have seen the news reports that The Scooter Store filed for bankruptcy in mid-April. The company had been under investigation for alleged Medicare fraud. These reports have resulted in questions from Members about the rules for obtaining a mobility device under Medicare. Here is the link to [the procedure](#) as established by the US Centers for Medicare and Medicaid. Remember, Medicare will not cover the costs of a PMD (powered mobility device) "if the use of the PMD primarily benefits the beneficiary in his or her pursuit of leisure or recreational activities." Or said another way, people must "have a personal mobility deficit sufficient to impair their performance of MRADLs (mobility related activities of daily living), such as toileting, feeding, dressing, grooming, and bathing in customary areas in the home."

Information and link provided by Jim Veccia via e-mail. 26 April, 2013.

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

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.



Coastal Empire Polio Survivors Assoc., Inc.
23 East 61st Street, Savannah, GA 31405
GA (912) 355-1221 • SC (843) 837-1230
E-mail: CEPSA05@msn.com
www.coastalempirepoliosurvivors.org

Shining Light on Post-Polio Health

CEPSA's next meeting is on
Saturday,
May 18, 2013
10:30 AM
at The Exchange on Waters
6710 Waters Avenue
Savannah, GA 31406

