

October, 2013 Newsletter

www.coastalempirepoliosurvivors.org

Vol. XVI, No. 8

# The President's Message...

 ${f O}$ ctober is the month that we focus on many special groups. Some



include Breast Cancer Awareness Month, Physical Therapy Month, Disability Employment Awareness Month, Mental Health Awareness Week October 6-12, and World Arthritis Day October 12. "We're Still Here," the annual October awareness campaign of polio survivors, has begun. World Polio Day is October 24. CEPSA was pleased to welcome Mr. Marcus Howard, a staff writer for the *Savannah Morning News*, to our September general meeting. He is planning an article for the paper later this month, focusing on local polio survivors and worldwide efforts to eradicate polio.

If you missed the September 28 meeting, you missed one of our best. Thank you to the attendees for telling or showing your solutions at the "Sharing Our Strengths/Showing Our Solutions" program. See Wanda Clas's excellent summary of the program on pages 4-6 of this newsletter. We have a creative and resourceful group.

To close my family's long, sad summer, we had a funeral service for my sister-in-law's son/my brother's stepson Richie on September 24 in Jesup. The minister's reading from 1 Corinthians: 13 was very comforting. As I

drove home, I thought about some of the verses and how they seem to apply to our CEPSA spirit. "Love is patient, love is kind...It does not boast....It does not dishonor others....It always protects, always trusts, always hopes, always perseveres....Love never fails...." As we celebrate the "We're Still Here" campaign this October, I am reminded that our love and support of one another have brought us this far.



Cheryl Brackin, President



Rotary's Livestream Event Thursday, 24 October 5:30 P.M.., CST #endpolio endpolionow.org

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Next Meeting Saturday, October 26, 2013 10:30 AM

Coastal Empire Polio Survivors Association, Inc.

## General Meeting Minutes September 28, 2013 Location: Exchange Restaurant

**Call to Order/Welcome:** President Cheryl Brackin called the meeting to order at 10:42am and welcomed everyone. She then introduced Marcus Howard from the *Savannah Morning News*. He was interested in learning more about PPS and planned to take notes and pictures.

**Pledge of Allegiance:** Michael Dunnermann led the Pledge of Allegiance.

**Program:** We next began our program (for Marcus's benefit), "Sharing Our Strengths/Showing Our Solutions."

Everyone participated discussing the topics of managing our lifestyles in the kitchen, sleeping and resting, getting dressed, and numerous other functions not normally thought of as a challenge, until PPS takes its effect. Many of the members brought in examples of their solutions and demonstrated how they work. Some of the items were handmade to demonstrate our skills to find answer to solve problems or complete tasks. Marty distributed a few copies of a catalogue called "Functional Solutions" (see page 4).

#### **Business Meeting:**

**Approval of Minutes:** Minutes from the June meeting posted in our September newsletter were approved as written.

**Financial Report:** The treasurer's report was given by Marty Foxx and approved as presented. She also read a letter from Cheryl's sister Shelia Tillman and noted she had given us a donation.

**Care Team Reports:** The care team leaders reported concerns about several members.

**Old Business:** Cheryl Brackin reported that we still have remaining brochure kits available for sharing our group information to reach other polio survivors.

Tom Schendorf and Harvey Varnadoe will be soliciting assistance from a local Rotary with another home modification for one of our members.

**New Business/Announcements:** The nominating committee for 2014 CEPSA officers and chairpersons has been appointed. Diane Davis will chair the committee, which includes Jim Veccia, Penny Smith and Cheryl Brackin.

Dan Shehan announced that he has collaborated on a music book, which currently is available for sale.

The meeting was adjourned at 12:20 pm.

Respectfully submitted, Michael Dunnermann, Vice-President/Secretary

**Attendance:** Cheryl Brackin, Carlos Clas, Wanda Clas, Della Simmons, Esther Simmons, Terri Dunnermann, Michael Dunnermann, Marty Foxx, Lavonne Calandra, Betty Goff, Harvey Varnadoe, Richard Graham, Penny Smith, Ross Smith, Tom Schendorf, Dan Shehan, Ann Chance, Dick Warden, Joan Page and Alan Page.

## A Note from the Treasurer



"CEPSA has 110 members. Many people receive our newsletters through email. We mail out 95 newsletters each month to members, their family members, and our sponsors. The postage and printing cost is \$181 each month. In 2013 we have

received dues from 48 members; thirteen of them have given \$670 in donations beyond dues. Our generous supporters and sponsors have given \$1,210 so far for 2013. The CEPSA Executive Board has approved an increase in dues for 2014 to \$20.00. Please consider making a contribution to CEPSA if you have not already done so for 2013. Dues are **optional** and appreciated from anyone interested in our mission. Thank you for your support and generosity."

Marty Foxx

## **Nominating Committee**

Diane Davis, Nominating Committee Chairperson with Cheryl Brackin, Penny Smith and Jim Veccia

You will be receiving or already had a call, asking you to fill a position on the CEPSA Board for 2014. Please consider becoming a board member. Our board is made up of members that have served for many years, and we would love to have other members participating.

If you feel that you cannot serve on the board, please consider helping one of our Chairpersons on one of our many committees.

# **Our October Speaker**

## James Aberson, Chatham County ADA Coordinator



James Aberson is the current ADA Coordinator for Chatham County, Georgia.

With over twenty years of experience as a disability advocate, Mr. Aberson says, "I

strive to work with governments and institutions to ensure that they are in compliance with the Americans with Disabilities Act. I am responsible for making sure all county buildings, services, and programs are accessible to all persons with a disability."

He has a Masters in Education from the University of Georgia, and conducts training in disability rights, advocacy, liability, and interaction. His specialties are in facilitation, arbitration, and as a government liaison.

Mr. Aberson will welcome your questions, including those from members who live in other areas.

# **Upcoming Meeting Dates**

**GENERAL MEETING** October 26, 2013 @ Exchange Restaurant 10:30 AM

\*\*\*NO Meeting in November\*\*\*

# Mark Your Calendar



Holiday Banquet



Hilton Garden Inn 5711 Abercorn St., Savannah, GA 31405

12:00 Noon

Our Holiday Banquet speaker will be polio survivor and author, Vaneetha Rendall Demski.

Vaneetha Rendall Demski is a freelance writer and has recently finished a memoir about her childhood, "Learning to Walk."

#### \*\*\*\*\*\*

Below is the menu for our Annual Holiday Banquet. You will be receiving a call from your Care Team Leader, asking if you will be attending the banquet on December 7, 2013, for total number attending, and your preference for your entrée. It is important that they receive an answer. If they leave a message please return their call. We need to have this information so the Hilton Garden Inn can order the correct amount of each entrée and know the number attending. There will be no assigned seating, so if you are coming with several people and are planning to sit together, seating will be open to choice. Those wishing to sit together with family or friends should arrive early.

### Banquet Menu Selection

#### Garden Salad

Iceberg Lettuce with Cucumbers, Tomatoes and Carrots. Served with Ranch Dressing.

Plated Baked Chicken Baked Chicken served with Rice Pilaf and Green Beans.

Plated Roasted Tilapia Roasted Tilapia served with Tomato Caper Relish, Rice Pilaf, and Vegetable.

#### Plated Vegetable Lasagna

Vegetable Lasagna served with Sautéed Seasonal Vegetables.

Dessert Chef's Choice of Assorted Pies

# World Polio Day 24/10

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

The World Polio Day social media presence is a Rotarian initiative to help create awareness of the ravages of polio and garner support for eradication efforts.

It aims to shed light on October 24th, which marks the month in which Jonas Salk was born (28th October). Salk was the leader of the team that invented the first polio vaccine in 1955.

In 1988 Albert Sabin developed an oral polio vaccine. This is what we're using today. It has reduced polio worldwide by 99%.

http://wpd.typepad.com/worldpolioday/about-us.html http://www.endpolio.org/resources

# New Documentary on Disability in the Media

#### by Mark Boatman - Jun 01, 2013

Portrayals of disability in film and television are as old as the media themselves, and filmmaker Jenni Gold examines these portrayals in her new documentary CinemAbility. "This film is able to showcase something a lot of people haven't thought about, which is how the media shapes social perception, and we investigate this important topic in an entertaining way," says Gold.

Gold's film explores the evolution of these perceptions through historical clips and commentary by entertainment heavyweights such as Ben Affleck, Jamie Foxx, Marlee Matlin, Helen Hunt, William H. Macy, Geena Davis, Gary Sinise and Geri Jewell. She says the celebrity support is vital because the film's message won't reach far if there's not an entertainment factor.

One of the topics the film explores is nondisabled actors playing disabled characters. Gold, who has spinal muscular atrophy, has mixed feelings about the phenomenon. "What you don't want to do is restrict art," she says. "If you could find someone that played Ray Charles better than Jamie Foxx I would be shocked. However, actors with disabilities need to be given the opportunities to try out for those roles, and often they are not." Gold says this issue and others are brought to the forefront in CinemAbility.

Gold's film premieres July 26 and will be taken on a 10-city tour this summer. For more information on the film visit www.cinemability.com

Reprinted with permission from New Mobility/newmobility.com, the magazine for active wheelchair users. Topic suggestion from an email from Cheryl Brackin to Wanda Clas, 12 Sept., 2013.

September 28, 2013 Program Highlights

## Show & Tell S.O.S Sharing Our Strengths or Showing Our <u>Solutions</u>

Our September 28, 2013 program definitely was fun and informative. Our members got the opportunity to share items and ideas that make their life easier and/or better.

Some members had more than one idea and were able to show how they have used their ideas or products to make their lives easier at home or out and about.

Marty Foxx brought copies of the catalog "Functional Solutions" for our members to keep. Marty suggested many ideas that she either has already bought or is thinking of buying for herself. She directed us to several pages (page numbers are listed after the items below) in the catalog that showcased these items. You can get your own copy of "Functional Solutions" by calling 1-800-821-9319 or online at www.ncmedical.com.

The following are some of the ideas that our members shared at the meeting. A few of these ideas were shared via email and others were found on the internet or mentioned by members of this group or other groups during previous meetings, in newsletters, or online.

Most ideas shared were inexpensive, simple and sometimes even free! Who doesn't love free?

Thank you to everyone who participated. Your ideas and solutions may change someone's life. They are listed below with the members' names.

### KITCHEN



• Use jar and bottle openers that provide a flexible, non-slip grip for easy opening of jars and bottles. (Suggested by Marty -See page 10) Some are even made to open smaller water, soda or medicine lids. Marty bought a Black & Decker jar opener (not in catalog) that she is very happy with.

• The "JarPop" allows you to open tight, vacuum-sealed jars with very little effort. (Suggested by Marty -See page 9)

• Using a stationary cutting board or one that has "food guides" that help hold your food items in place while you cut, is helpful to those with limited grasping ability and those with arthritis. (Suggested by Marty -See page 8)

• For those experiencing weakness in the hands and arms, a compact one-touch chopper makes quick, easy work of chopping and mincing. (Suggested by Marty -See page 9)

• Foot pedals on your kitchen sink make operating the faucet easier when reaching is a problem. This idea can also be used in the bathroom sink. (Suggested by Marty)

• The "Baggy Rack" by Jokari can hold your food storage bags for you while you fill them. It's like having an extra set

of hands! You can also use them to hold washed or recycled storage bags while they air dry. Available at Publix supermarket. Price may vary according to store. (Suggested by Cheryl)

• Use a stool to sit while preparing food in the kitchen. Some stools are even counter or bar height that allow you to sit almost in a standing position if you need to get up and move about often. (Suggested by Cheryl)

#### EATING

• Many of us don't eat as much as we used to as we age. When eating out, order a full meal and split it in half. Take one half home for a simple, ready-to-eat meal the next day. Only minimal effort required. A



couple dining out together can order two different meals and switch meals the next day, allowing you to eat two completely different meals. (Suggested by Ross)

• Using a bib when needed helps keep your clothes free of dropped food and spilled drinks when you have limited mobility or strength in your hands and/or arms. This is a great idea for anyone wanting to keep their clothes looking fresher longer. Less washing and less work means preserving your energy. (Suggested by Marty)

• If you are having trouble swallowing or are choking when eating, you may be experiencing dysphagia. The suggestion is to tuck your chin into your neck when swallowing. This was suggested to Penny by a medical professional, and it helps to make swallowing food easier. (Suggested by Penny)

### FUNCTIONAL

• The "Lever Extender" extends the length of the handle on recliners, making it easier to reach and control. The handle makes it possible not to have to bend over. This item is especially helpful for those of us who use our recliners as our primary sleeping surface and those using a recliner while recovering from surgery. (Suggested by Marty -See page 17)

• Spring-action scissors are great for those with arthritis or



scissors are great for those with arthritis or limited hand strength. They make quick work of cutting things with less effort. Marty suggests having a pair of scissors in

every room for various cutting uses. (Suggested by Marty)

• Doorknob grippers or extenders haven't worked as well for Marty as have levered doorhandles. The levered handles can be opened easily even with a closed fist, elbow or one or two fingers. These vary in price and can be found at your local hardware or home improvement store. (Suggested by Marty)

• Rocker switches also work well when you need to turn on lights easily. Much more simple than the traditional light switch that you need to "click" on and off. Marty says pull chains on lights are useful. Changing the regular switch on lamps to knob-style makes turning the lamps on and off an easier task. (Suggested by Marty)

• Rocker-style adapters are available at local home

improvement stores. These inexpensive switches first plug into any wall outlet. You then plug your lamp or other continuous electrical item into the switch. You can now control the item from the switch. You can even use your foot to work the switch. These are great for hard to reach knobs on lamps. You will no longer have to reach under the lamp. The switch can be positioned closer to your bedside or recliner for easier access. (Suggested by Carlos)

• A "Clapper" or "Clapper Plus" can be used to plug in your Christmas tree lights, lamps and sometimes even your TV. The item can then be turned on by clapping your hands. If you are not able to clap your hands, the "Clapper Plus" has a remote that allows you to turn on any two items with the remote from as far as 30 feet away. (Suggested by Marty)

• Using a zipper pull or a button hook helps making dressing easier. Great for those who have a hard time grasping or pulling a small zipper pull or pulling buttons through small button holes. (Suggested by Cheryl for Lorraine)

• On that same note, keep a pair of dollar store reading glasses in every room for those times that you forget your "good" glasses in another room. You don't have to go back to the other room right away. Great for reading the instructions on items in your medicine cabinet or on beauty products. A pair of glasses that flip down sides alternately while you apply make-up is very useful for those of us who have vision problems. These are also useful when you feel you have a foreign object in your eye, but still need to have glasses on to see that object. (Suggested by Wanda)

• Use a key holder with an extended handle that makes it simpler to use your house key or turn your car on. Lorraine once showed our group the key holder that she had to start using while experiencing weakness in her arm and hand after surgery. Harvey says some keys might not fit in the key holder and you may need to go to a locksmith who can make an alternate shaped version of your key to fit inside the key holder. (Suggested by Harvey)

• Office Depot sells a letter opener that also cuts coupons and Office Max has a pen called "PenAgain" that fits inside your hand to make writing easier. (Suggested by Marty)

### Sleeping / Resting



• A soft micro-bead filled pillow that is shaped like a cylinder can be placed behind your knees or between your knees to relieve pressure. Stack 3 regular pillows to relieve swelling in your legs. (Suggested by Cheryl)

• Roll up a towel and place under your neck when lying down to relieve pressure on the neck. This is a great no-cost alternative to a pillow. (Suggested by Lavonne)

• Fall asleep faster by keeping your eyes open while trying to fall asleep. This tip sounded funny, but it really works. Your mind will be focused on what you can see or imagine seeing, if it is dark. You will not be focused on what you are thinking. Sometimes we are focused on trying to fall asleep and fail at it. How many of us are having sleep problems? This may be a

solution. (Suggested by Ross)

• Having your bed at a good height makes getting in and out of bed much easier. Marty finds it useful to roll onto her stomach and then "throw" her feet off the side of the bed to get out of bed. (Suggested by Marty)

#### Bathroom

• A hand-held shower is useful if you need a lower shower head, have to direct it on hard-to-reach areas or if you have to sit while bathing. (Suggested by Penny)

Use an attachment that allows you to hook your hand-held

shower at a lower position. Betty bought hers on QVC, and there are versions available that suction onto your shower wall or can be permanently affixed to the wall at your ideal height. (Suggested by Betty)

• Rubber floor mats that have little "tentaclelike" peaks adhered to the shower wall can be used to easily wash your back. Make sure you use stainless steel screws and washers so that they don't rust. (Suggested by Marty)

• A goose-neck dryer stand can help hold your hair dryer if you are having trouble holding the dryer or if the dryer is too heavy to hold. The dryer on the stand can also be used to dry yourself after after a bath or shower. The goose-neck can be directed easily. (Suggested by Marty)

• Have a vanity stool available in the bathroom that allows you to sit while brushing your teeth, applying make-up or grooming. (Suggested by Marge)

#### Auto

 Gas and brake pedal modifications allow you ease of movement when driving your car.
Perfect for those that have limited mobility, weakness or problems reaching the foot pedals in their car. \*\*\*Please have any

modification to your car done by a licensed professional. (Suggested by Joan and Alan Page)

• The "Handybar" allows you a safe and convenient way to get in and out of your car. This item locks onto the existing door frame, is easy to install and can be used on either the driver or passenger side of the car. It supports up to 500 lbs. (Suggested by Richard)

• Put a pair of "grabbers" or tongs in your car for those times when you drop something in the car. A good way to retrieve items. (Suggested by Dick)

• Adding a small piece of poster tack to a long stick can help you pick up tiny objects from the floor, like earring backs, small screws from eyeglasses and buttons. These hard-topick-up items will stick to the poster tack and can be picked up easily. There is no damage to the object, and it can be left on the stick for future use. Use a smaller stick for hard-topick-up items on tables or counters. (Suggested by Wanda)

· Penny uses a firm pillow behind the small of her back to

keep her comfortable and supported in the car. This helps on long car trips. (Suggested by Penny)

DIY

• Many polio survivors have one foot that is smaller than the other. This makes it hard to buy shoes and slippers that fit both feet properly. Buying shoes in two sizes solves this problem, and you can list the other two odd shoes on OddShoeFinder.com. You can also purchase shoes with two different sizes at this site. (Suggested by Carlos)

• If you have a pair of slippers that are strapless and they

keep falling off, you can attach an elastic to your backless slipper with 2 large safety pins, one on either side. Make sure the elastic is cut to fit your "smaller" foot plus enough elastic to be able to pin on. This solves the problem of tripping because of



your too-large or too-loose slipper. (Suggested by Carlos)

• A small piece of cushion covered in a fabric matching the color of your brace can alleviate any rubbing caused by the brace on your skin. It can also fill in any empty areas between you and the brace for those that were left with a thinner leg or legs from polio. Attach a piece of Velcro to the finished cushion and a piece to the inside of the brace. The cushion can then be removed and replaced as needed. You can use double stick sewing tape to create the cushion if you don't sew. (Suggested by Carlos)



• A walker with a seat and 4 wheels can be useful when transporting laundry or heavy dishes. Use the seat to hold your items as you push your walker. For lighter or smaller items, use the basket if your walker has one. This method allows you to safely hold

onto the walker with both hands.(Suggested by Betty)

• Dick uses a lightweight folding walker that he can carry and open by himself. It is easy to transport in the car and light enough that he can retrieve it while out and about. (Suggested by Dick)

• A calendar with large enough areas to write on is an ideal way to keep track of appointments and doctors. Write your appointment time, doctor's name and a brief description about your visit. Other appointments and events can also be written down. SAVE all your calendars in a safe place. These become small diaries that you can reference when you forget a doctor's name or date of surgery, for example. (Suggested by Wanda)

· File warranty and instruction information for household items inside sheet protectors housed in an inexpensive binder. Label the sections according to items, e.g., appliances, TV's and lawn equipment. Don't forget to insert the warranty card and write the date when you send out the card. Flip to a section and then to an item quickly when an item breaks down or you need to remind yourself how something works. No more wondering where the warranty

book is. (Suggested by Wanda)

• Set your microwave timer to remind you when to check on something cooking on the stove. Set it to send you a reminder to check on your food or to turn your stove off. Set your cell phone alarm to remind you to recharge your scooter batteries every week or two. (Suggested by Wanda)

• Take a stool along with you when going to events or gatherings where you might be standing. (Suggested by Marge)

• E-readers are a great way to enjoy a good book without the weight of the book. You can take them along to appointments and other places where you like to read. (Suggested by Cheryl)

• Items installed on your car by an unlicensed person will make your auto insurance null and void. The insurance company will not pay if you have an accident because you altered the way the car was originally. Use a licensed professional. (Suggested by Richard)

• CEPSA health forms that are fill-able and printable on your computer are now available. We will have them available on our website soon. In the meantime, if you need one, ask Lavonne or Wanda to send you a blank form that you can fill out at your convenience. Print these and update as needed and as your information changes. A printed version is available if you do not have a computer. This is a great way to have your medical history ready for your doctor if you can't fill out those long forms at the doctor's office. (Suggested by Lavonne)

#### More Ideas

 Buy fans with remotes that you don't have to get up to turn on or off.

· Increase lighting around the house for safety. We lose vision as we age and need better lighting.



 Install an extra long hose on your kitchen sink sprayer.

• If you need a little extra room through doorways, install swing-away hinges. This type of hinge allows the door to open all the way away from the door frame.

• "D" shaped handles on kitchen and bathroom cabinets and on dressers are easier to pull than knobs.

• Remove cabinets under sink to create more space for a wheelchair to fit. \*\*\*Make sure you insulate the pipes under the sink to avoid burns.

• Tilt mirrors at the top. This makes it easier to see yourself if you are in a wheelchair or if you have to sit while grooming.

• A covered travel cup keeps hot liquids in while you go from room to room and keeps your drink hot longer.

• Replace a pre-code shower valve with a non-scald one.

From notes taken by Wanda Clas at the Exchange Restaurant on September 28, 2013.

# Polio's second act

**by Kate Nolan** The Rotarian - September 2010



Illustration by Bonnie Hofkin

Ina Pinkney has made the best of polio. Her baked goods win national acclaim, and foodies wait for seatings at Ina's, her culinary star turn in Chicago, where she is known as "the breakfast queen."

Diagnosed with polio at 18 months in 1944, she was treated by the famed Australian nurse Sister Elizabeth Kenny, whose then-controversial therapy involved boiling strips of wool, wrapping them around the affected limbs, and using massage to alleviate muscle spasms. After a month of the painful regimen, Pinkney was walking again, but the disease had caused lasting damage. For years, she exercised to retrain her muscles, but her right leg never caught up with the left.

Pinkney remembers going to a gala in New York as a young woman. Count Basie played, and her idol, movie star Fred Astaire, was there. She walked over to him, and Astaire said, "I see you have some difficulty walking. Let's just pretend."

"He took me in dance position, and we swayed, maybe 12 times - 12 sways with Fred Astaire, a very big moment," she recalls.

Pinkney now experiences "mind-numbing" fatigue, her leg feels weak, and she has tried exercising to strengthen it. She reluctantly agreed to be fitted with an ankle-foot orthosis (a brace) and wore it home from the doctor's office. Leaving the office, she fell in the street. Pinkney, 67, calls the episode a "gut blow." "It told me I had a lot of work to do," she says. "I had to learn to walk with the brace and, more important, I had to accept it."

#### Postpolio syndrome

Pinkney's polio had not come back, but she had postpolio syndrome, a set of debilitating symptoms that strikes survivors at least 15 years after they've had the disease. As many as 55 percent of an estimated 775,000 polio survivors in the United States may be at risk of developing it.

"We'd see more support for polio eradication if people understood the long-range effects of the disease," says Ann Lee Hussey, chair of the Rotarian Action Group for Polio Survivors and Associates. Like many Rotarians who are polio survivors, she is a strong advocate for Rotary's US\$200 Million Challenge. "There are many polio survivors who serve as their district PolioPlus chair and are active in fundraising. I traveled to Hong Kong for an event that raised \$250,000."

Many people have not heard of postpolio syndrome. Compared with the 20th-century epidemics that spawned a national movement in the United States led by President Franklin D. Roosevelt, it's an understated illness. Many patients who have postpolio syndrome – an underdiagnosed, under-researched condition without broadbased advocacy from patients – don't even know it's related to the disease.

It has been 26 years since postpolio syndrome was identified, but often doctors don't know how to diagnose or treat it, Hussey says. Because polio is viewed as a conquered disease in the United States, its aftermath has been relatively unexplored in the research and in medical schools.

Post-Polio Health International, a St. Louis group that works closely with the Rotarian Action Group, addresses the dearth of information through a network on its website, www.post-polio.org. It connects patients with each other and the few health professionals experienced in treating the condition.

A new tide of potential patients rises in the developing world.

Most of the people who lived through the U.S. polio epidemics will die in the next 40 years – a fact that may offset the irony that the final phase of the most studied virus in history now gets modest public notice. But even greater resources may be needed in the future, as a new tide of potential patients rises in the developing world.

"They're going to have horrible lives. Who will address their pain and mobility issues?" Hussey asks.

For Daniel J. Wilson, having postpolio syndome means managing a growing list of things he can't do anymore. "I can't walk all over Paris and take the metro," says Wilson, 60, a professor of history at Muhlenberg College in Allentown, Pa., and the author of a well-regarded history of polio in the United States, *Living with Polio: The Epidemic and Its Survivors*.

Wilson contracted the disease at age five, his mother doctoring him with the hot packs that had become common. The weakened muscles of his right torso led to scoliosis, a type of spinal disfigurement. At 10, he had spinal surgery that put him in a body cast for six months. He completed fifth grade at home in Wausau, Wis., and regained his strength. He later earned his doctorate from Johns Hopkins University.

### The first signs

The first sign of postpolio syndrome came in the mid-1980s, when Wilson had trouble lifting his right foot off the gas pedal to brake his car. Soon his right leg began giving out while he walked, and he experienced increasing muscle pain. His wife, Carol, started carrying packages for him. Now he sits while he lectures, walks with a cane, and uses a scooter for longer distances. When his beloved wheaten terrier Abbey died at 16 last year, he decided against getting another dog because he couldn't walk one anymore. He installed a stair lift at home, preparing for when he can't handle stairs.

"I live with the certainty that I can't trust my body anymore," Wilson says.

Abraham Lieberman, 72, medical director of the Muhammad Ali Parkinson Center at Barrow Neurological Institute in Phoenix, started to have difficulty walking in the late '90s and sometimes used a walking stick. By 2001, his left leg was failing, and he diagnosed himself with postpolio syndrome. He has no joint or muscle pain but suffers weakness in his legs.

"I'm not happy about it, but I'm not going to die from it. I'd be happier if I were 10 years younger," says Lieberman, who was hospitalized with polio in 1944 at age six in New York with nearly full-body paralysis. His mother wrote to Roosevelt for help, and the sympathetic president wrote back, saying he would do what he could. Lieberman's young life became a cycle of braces, injury, and surgery, but left him with strong hands and the ability to walk without assistance. He finished medical school, served in the U.S. Air Force as a doctor in Japan, and later specialized in research on Parkinson's disease.

"You can manage the pain and fatigue, but there's no simple test for it," says Julie Silver, assistant professor at Harvard Medical School and former director of the International Rehabilitation Center for Polio at Spaulding Framingham hospital in Massachusetts. "It's a diagnosis of exclusion." After thyroid problems and sleep apnea have been ruled out as causes of fatigue, for instance, postpolio syndrome may be considered in a patient who has slowed down. There's the shock of realizing that they aren't finished with polio.

At the rehabilitation center and the handful of other facilities across the country specializing in postpolio syndrome, an assessment typically includes an examination by a doctor experienced in the condition, a nerve and muscle study, and sessions with physical and occupational therapists, a brace specialist, and a psychologist.

The psychological fallout of a diagnosis can be dramatic. "It feels like a double whammy," says Silver, author of *Post-Polio Syndrome: A Guide for Polio Survivors and Their Families*. First, there's the shock of realizing that they aren't finished with polio, and then that no recovery from postpolio syndrome is in view. Care recommendations can include home modifications, a brace, stress management for fatigue, lifestyle changes such as reduced work hours, and devices to help with breathing and mobility, alleviate pain, or prevent falls.

In the 1950s, polio survivors learned to exercise during rehabilitation, often in great pain. The new field of physical therapy strongly linked determination with overcoming physical challenges. Charles Atlas was telling men they could build a muscular body through willpower and isometric exercises, and Norman Vincent Peale in *The Power of Positive Thinking* was saying attitude was everything. Both ideas were part of American culture then.

"When you went into rehab, the emphasis was on pushing as hard as you could, like the Little Engine That Could. Physical therapists and families pushed polio survivors to achieve the maximum results, and in many cases substantial recovery was possible," Wilson says. "We had won World War II, and we were moving forward. Men had a lot of concerns about masculinity and proving they could take it. Dealing with painful physical therapy demonstrated you weren't a sissy."

### More harm than good

Pinkney recalls the pressure she felt from the public campaign against polio. "How could you let anyone down, with all of them on your side? Polio children learned to be such good children," she says.

Then, years later, came postpolio syndrome. Research showed that the exercise that had been recommended actually did more harm than good. Unlearning the old rules was as much a cultural shift as a medical one, says Wilson, whose book devotes a chapter to the illness. Deemphasizing exercise initially strikes many survivors as backward.

To overcome her postpolio fatigue and weakness, Pinkney went back to the old playbook. "But it hurt me," she says. "I'd be in better shape now if I hadn't exercised." Today she walks with a cane and predicts she will rely on a wheelchair full time within six years. These realities are familiar to Lauro Halstead, director of the postpolio program at the National Rehabilitation Hospital in Washington, D.C., and a key figure in the story of postpolio syndrome. In 1984, Halstead organized the first medical conference devoted to the condition.

In the 1970s and '80s, survivors started reporting symptoms reminiscent of polio. Patients and doctors feared the virus was back. Other doctors suspected the chronic condition fibromyalgia or multiple sclerosis. Some told patients the symptoms were in their heads. To make sense of the reports, Halstead, then a doctor at the Institute for Rehabilitation and Research at Baylor University in Houston, organized a national meeting of experts at the Roosevelt Warm Springs Institute for Rehabilitation in Georgia, the polio center founded by Roosevelt.

The neurological system makes adaptations that can wear out the surviving motor neurons.

A polio survivor in his late 40s, Halstead was having unexplained leg pains himself. He had polio after his freshman year of college and split the next year between an iron lung and a wheelchair until he regained his strength. He lost the use of his right arm and hand but taught himself to write left-handed and finished his schooling. Becoming a spinal cord injury specialist at Baylor, he assumed polio was behind him until the pain returned.

"The leg pains were very like the leg pains I experienced during the acute phase of polio. Fortunately, there were a lot of hotshots at Baylor to look into it. It wasn't polio, but nobody could figure out what it was," says Halstead, 74, editor of *Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome*.

Then he read an article by David Wiechers, a researcher at Ohio State University who was working with electromyographic diagnosis, which monitors electrical activity in the muscles to diagnose neuromuscular problems. Wiechers had tested some polio survivors who had the same symptoms and noticed surprising neurological changes. His work raised more questions than it answered, though.

Media were riveted to the notion that polio was back, which generated plenty of publicity for Halstead's conference. But the triumph of the event was setting a research agenda. Studies would show that polio was not back. Fragments of the virus were found in patients but weren't reinfecting them. Researchers soon named the new disorder and clarified its characteristics.

Now the pathology is clear. During the acute phase of polio, patients can lose motor neurons, the nerves that carry signals to the muscles. More than 50 percent of them can experience weakness and possibly paralysis. The

neurological system makes adaptations that can wear out the surviving motor neurons.

Imagine a right arm attacked by polio and an unaffected left arm, Halstead says. The right arm's dead nerve cells no longer stimulate the muscle, so the muscle atrophies but still sends out a chemical signal that instructs the healthy left arm to develop more "axon sprouts" – the endings on the motor neurons where chemical changes take place for muscle stimulation. Catastrophically, the number of sprouts increases.

#### Neurons

"Think of the tremendous metabolism it takes to generate the chemicals needed by each axon sprout. The motor neurons get worn out. That accounts for the new weakness in the muscle," Halstead says. Exercise is thought to spur the unwanted growth of new sprouts.

Questions about postpolio syndrome still outnumber the answers: Why do some people get it while others don't? What might cure the condition? Can it be prevented?

There's not much new in the research. Postpolio syndrome has always been an orphan disease – the crisis of the few since polio became a footnote in U.S. history. Before the illness was even identified, the once polio-centric March of Dimes had changed its focus to birth defects.

Some work continues. The John P. Murtha Neuroscience and Pain Institute in Johnstown, Pa., is exploring nonfatiguing exercises and stress-reduction behaviors at its polio-survivors clinic. Studies in Canada, France, Norway, and Sweden show that the immune system may have an influence on postpolio syndrome, and interest in a long-term U.S. clinical trial to replicate them is growing. Research may lead to a gamma globulin shot to reduce symptoms.

Halstead says studies have fallen off in the past 5 or 10 years, as U.S. polio survivors die and the medical complications of aging make it harder to research them. But the syndrome could continue for years.

"It is just now becoming an issue in India, and it will be eventually in all areas of the developing world as the average lifespan increases," says Hussey, of the Rotarian Action Group. While Rotary's eradication efforts have dramatically slowed the rate of polio infection, the World Health Organization estimates that survivors number between 10 and 20 million worldwide. "Long after the last polio case, postpolio syndrome will persist as a significant personal, social, medical, financial, and political challenge," Hussey says.

Nolan, Kate. "Polio's Second Act." The Rotarian Sept. 2010: 30-37. Print.

Reprinted with permission via telephone from Rotary to CEPSA's New Member & Accessibility Awareness Chairperson, Harvey Varnadoe. Article Submitted by Harvey Varnadoe & Diane Davis.

# Polio's forgotten strongwoman

**by Mohamed Khairat,** Communications Assistant for The End of Polio.



From Rosa Parks and Mother Theresa, to Oprah Winfrey and Hilary Clinton, the accomplishments of women are today widely recognized.

In the past, the achievements and talents of many women were often ignored by a male-dominated society, and remain unknown or forgotten by today's society.

One of these women often forgotten about by established historical textbooks and by activists closely following the campaign to end polio is Dr. Mary Putnam Jacobi.

Few people have ever heard of Dr. Jacobi, who was not only the first female graduate of the Ecole de Medecine in Paris in an era where so few women gained admission to medical schools, but was also one of the first scientists to speculate that polio was caused by an infection.

Ahead of her time, Dr. Jacobi published a 50-page chapter on infantile paralysis (polio) in 1886. In this research she hypothesized that polio was caused by an unknown member of 'the great class of pathogenic bacteria'. Dr. Jacobi also exposed that polio struck the part of a human spine that contains motor neurons.

Yet, despite this breakthrough and despite becoming the first woman admitted to the New York Academy of Medicine, Dr. Jacobi's research was largely ignored, thanks to traditional ideas about the weakness of women, only to be rediscovered some 20 years later.

Nevertheless, it would be difficult to describe Dr. Jacobi as "weak." Throughout her lifetime, she inspired and empowered a new generation of women to work towards becoming physicians, and – unlike other thinkers – believed that women and men should be equal when it came to contributions towards clinical medicine.

Shortly after Dr. Jacobi passed away at the age of 63 in 1906, female scientists started becoming better known – and essential – in the medical world. One of these women was Isabel Morgan, whose work became a key element in the progress towards developing Salk's polio vaccine.

Today, thanks to the work of a strong network of individuals

and groups battling to end polio, we are just 1 percent away from ensuring that the disease never cripples a child again. It is thanks to the work of each individual – even those who are often forgotten like Dr. Jacobi – that we have been able to reach this historic moment.

Women make up half of the world's population and yet represent a staggering 70% of the world's poor.

# **Success!** The US Senate requests \$207.1M to end polio

### **by Judith Rowland,** US Campaigns Associate

It has been an exciting journey.

Over the past two years, The End of Polio campaign has worked in partnership with members of the Global Polio Eradication Initiative (GPEI) to push world leaders to support and fund critical polio eradication programs. Through the 2011 End of Polio Concert in Perth, Australia and the 2012 Global Citizen Festival in New York City, we built public support for polio eradication and called on world leaders to end polio forever.

Global Citizens have rallied together so that no more children have to suffer from the scourge of polio. Over 62,000 people have signed the End of Polio Petition, 22,000 supporters have written emails to their politicians urging them to advocate for polio eradication, and The End of Polio team has had 33 meetings on Capitol Hill to show United States leaders the groundswell of support for polio eradication. After receiving emails from End of Polio supporters and meeting with our team, Senator Collins (R-ME) said, "As the Senate discusses the fiscal year 2014 budget, I will keep the views of those who have signed this petition for polio eradication in mind."

Polio cases have been reduced by 99.9% since 1988 and leading experts on the Independent Monitoring Board of the GPEI believe that polio transmission can be stopped by the end of 2014.

Earlier this year, world leaders joined together at the Global Vaccine Summit and pledged \$4 billion to end polio by 2018. Pledges included £300 million from the British government, \$250 from the Canadian government, and \$1.8 billion from Bill Gates on behalf of his foundation. The momentum of the Summit led the Australian government to commit an additional \$80 million for polio eradication.

Your diligent advocacy has helped build advocates for polio eradication within the Senate. Senator Kirk (R-IL) said, "I support The End of Polio campaign and hope that we can

soon see a world that is free from polio." Senator Durbin (D-IL) explains that, "We are closer than ever to ending the scourge of polio and I commend the work of Rotary and many others in advancing that goal." Just last week the United States Senate confirmed a \$207.1m request for polio eradication. This request is a huge step toward seeing the end of polio.

But the journey isn't over. The House and the Senate have each submitted budget requests and now a separate committee will negotiate a finalized budget. We need your support to ensure that the Senate's request is upheld.

The challenge now will be for the budget requests from the House and the Senate to be negotiated into a final budget. There is still work for us to do: the House requested only \$48m for USAID.

We have a huge opportunity here to solidify a funding increase for polio eradication in 2013. This is massive, guys!

Share this news with your friends and followers on Twitter, Facebook and Google -- and make sure to let your representatives know that you support the Senate's budget request!

**"Polio's forgotten strongwoman"** on page 10 and **"Success!** The US Senate requests \$20.1M to end polio" on this page were brought to you by:



Polio - a disease that has disabled millions and pulled people further into poverty - has been reduced by 99% since 1988.

Thanks to a global partnership involving Rotary International, the World Health Organization, the US Centers for Disease Control and Prevention and UNICEF, more than 2 billion children have been vaccinated against polio and more than 8 million are alive and walking today. In January, the world reached a remarkable milestone in the fight to eradicate polio – 12 months without a case of polio in India for the first time in history.

But progress towards eradication is at risk. The critical work of the Global Polio Eradication Initiative (GPEI) is currently constrained by a funding gap of \$945 million for 2012/13 threatening international polio eradication efforts.

The End of Polio campaign is working with partners such as Rotary International, along with governments and the broader community, to support the GPEI and make the end of polio a reality.

For more visit theendofpolio.com.

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To Become a Global Citizen, go to: <u>www.globalcitizen.org</u>



# Tips for energy conservation:

- Remember, with muscle weakness your muscles have to work much harder than healthy, non-polio muscles. Energy conservation is a must.
- Plan your activities. This includes rest periods.
- Prioritize your activities. This will maximize your usefulness when performing them.
- When resting, try to lie down.
- Sit, whenever you can, when performing tasks.
- Use proper body mechanics. Proper body mechanics place less strain on your muscles and joints. This may require the use of various orthotic devices or gadgets as recommended by your occupational therapist.
- Use ambulatory aids when moving for long periods of time or long distances.
- Do use a scooter for longer distances if your shoulder joints are wearing out from decades of walking with axillary crutches.
- Find out about all the new devices which can work around the home and work-place easier. Try them out before you reject them.
- Look at the positive rather than the negative. Aids are, by definition, designed to help, not hinder. Make them work for you.
- Get adequate sleep.

Reprinted with Permission from Easter Seals of Nova Scotia. Please visit the following link to read the entire booklet.

<htp://www.easterseals.ns.ca/wp-content/uploads/2009/06/Polio:Nova-Scotia-Late-Effects-Guide-for-Polio=Survivors.pdf>.

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### Happy Birthday



October November Carlos Clas - 1 Billy Ray Washington - 3 Mildred Roberts - 4 Eileen Boyle - 5 Dan Shehan - 6 Hattie Evensen - 7 Rev. Edward Ellis - 11 Skeet Varnadoe - 15 Michael Dunnermann - 16 Linda Munn Graham- 19 Adrienne Stallworth - 31

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

#### Member Concerns

Janet DiClaudio, Archie Ivy, Bobby Johnson, Patrina

Please keep these members in your prayers.

#### Condolences



My mother passed away this afternoon. She was 95 years old and lived a very remarkable life. My sister and I and several of our children were with her as she passed peacefully. Tomorrow will be my brother's birthday who passed away about 5 years ago and I pray that she and my brother will celebrate together.

Love to all,

Penny

Our condolences to Penny and Ross Smith and their family on the loss of Penny's mom. We are so sorry for your loss. Your mom, brother and family are in our thoughts and prayers.

From an email from Penny Smith to Jim Veccia, 21 Sept., 2013.

CEPSA would like to offer condolences to Cheryl Brackin, her brother Thad and his wife Kathleen on the death of Kathleen's son and Thad's step-son, James Richard "Richie" Harper. Richie was only 46 when he passed away in his home on September 21, 2013. Please keep them and their family in your thoughts and prayers.

#### **Prayer Request**

I had a long phone conversation with Liz Colson this afternoon to get the latest on Janet. (The staff told me very little when I was there last week.) Liz's name is the only one on Janet's HIPAA form. Liz is sick and has been texting with Dr. Lorenz, pulmonologist, rather than going to the unit. Dr. Lorenz is trying to wean Janet off the ventilator and the morphine. She does have congestive heart failure. When she is alert again, the doctor wants to talk to her about her treatment plan. Janet's feeding tube was clogged, but hopefully has been cleared and is working now. As long as she has normal brain function, the doctor wants to continue lifesavina treatment.

Liz sounded hopeful about Janet. Let's continue to pray that she will come out of this as she did once before. Janet truly is a fighter and a survivor.

#### Chervl

From an email from Cheryl Brackin to Jim Veccia, 10 Oct., 2013.

## Congratulations



Jamie Huyer and I were married August 2 at the gazebo on the dock in front of our new apartment on Ladys Island, Beaufort. In attendance were most of my children and two arandchildren. It was very informal and small with smiles all around. Jamie did ballet for 20 years before going into marine biology and later teaching adults economics and finance at the Univ. of Missouri. She was born in Puerto Rico and lived in Cuba until the revolution then her family moved to Greenwich, Conn.

Warm regards to all, Richard Warden

From an e-mail from Richard Warden to Wanda Clas 5 October, 2013.

Congratulations to Dick and Jamie from all of us at CEPSA. May you have many years of happiness together.

Congratulations to Dan Shehan, who along with Joseph Cecil Wingard, published a wonderful book of original songs, "Christmas Songs." The book contains the lyrics and music to 25 songs. It can be a great addition to your music collection as well as a very unique Christmas gift that can be treasured for years to come. The book is available for purchase by contacting Dan Shehan at <u>danshehan33@comcast.net</u>.

Congratulations to Esther Simmons who is introducing her newly released poetry book, "Esther's Book of Original and Inspirational Poetry." It is on sale now at E. Shaver Booksellers in Savannah, Georgia. The book can also be purchased by contacting Esther at www.esthergsimmons.com. The original single gospel CD entitled "Do You Believe?" is also available for puchase.

Esther announced that after seven years working at the television station WTOC in Savannah, she is leaving to pursue other interests. She was celebrated at the station with an on-air goodbye and not one, but two cakes! We wish her well and good luck with her new ventures.

## Notes from Friends & Supporters

#### Hi Marty,

Hope you are doing well. Please keep me on the rolls and give my best to the members!

*Kindest Regards, Anne* (Dr. Anne Thompson)

From a note from Dr. Anne Thompson to Marty Foxx.

This contribution is made in honor of my sister, Cheryl Brackin; and with deepest appreciation to all the CEPSA family for the many caring thoughts and prayers during our long, sad summer. We are grateful for the support.

Praying God's blessings on all the membership. Sheila Tillman

From a note from Sheila Tillman to Marty Foxx, 21 Sept., 2013.

## Members In the News

CEPSA members Penny and Ross Smith were part of a volunteer group of about 40 who filled about 200 boxes with medical supplies at MAP International. MAP International is a Christian health organization that has shipped \$4 billion in medicines to economically poor nations since 1954. Penny and Ross, as well as other volunteers, appeared on the cover of the Life section of THE BRUNSWICK NEWS, 15 August, 2013. The article was cleverly titled "HELPING THE WORLD WITHOUT LEAVING THE COUNTY" by Sarah Lundgren. We are inspired by them and are so proud of the work they are doing to help others.

Ross was also featured on the cover of THE ISLANDER,

05 August, 2013. Ross and some of the volunteers of the International Seafarers' Center were featured in the article "Volunteers keep Seafarers' Center Moving" by Pamela Permar Shierling. These volunteers support and provide various services to the roughly 500 ships that dock each year at the Port of Brunswick.

### Quote of the Month



"October gave a party; The leaves by hundreds came-The Chestnuts, Oaks, and Maples, And leaves of every name. The Sunshine spread a carpet, And everything was grand, Miss Weather led the dancing, Professor Wind the band." -George Cooper, October's Party

# DID YOU KNOW ...

your voluntary dues help us cover the cost of producing this newsletter? The newsletter is a vital part of our effort to share information about polio and Post-Polio Syndrome.

Your generosity and participation also allow us to fulfill our commitment to the CEPSA Purpose Statement.

If attending our Holiday Banquet, why not add your \$20 voluntary dues to your banquet check? Your support keeps us going. We appreciate all those who paid their dues this past year.

> A special thank you to our supporters and sponsors. Your generous donations allow us to continue our efforts to "Inform, Assist, Support and Counsel."

Your contributions are tax deductible and will be acknowledged appropriately.

Let's make 2014 our best year ever. Together anything is possible.

"I alone cannot change the world, but I can cast a stone across the waters to create many ripples." -Mother Teresa

www.coastalempirepoliosurvivors.org

# The Myth of In-Utero Polio by Edward Bollenbach

Recent questions on Internet polio lists have unmasked concern, among some, that they may now be affected with the post-polio syndrome (PPS) because their mother had polio while pregnant carrying them. Another worry, again expressed on Internet discussion lists, has been that the PPS is affecting the children of women who were pregnant while infected with polio because the virus damages the fetus during pregnancy. Concerns like these extend even to the mother, who has had polio in her history, although not during pregnancy, and now believes that her children are predisposed to develop post-polio syndrome. This has been imagined as a cause for the children's current perceived problems (back and leg related, for example) with an explanation served up by the mother's history of polio.

Let's look at the last concern first. There is no theory of PPS that could explain how someone who had polio in the past and later became pregnant could confer a predisposition to PPS to their offspring. The idea, in a way, reminds me of the disproved Lamarckian evolution theory, which attempted to explain why giraffes had long necks. The idea was that years of stretching to the high leaves elongated the giraffe's necks and after mating they passed on their long neck acquired trait to offspring. Today we know better. Traits are passed to children through the DNA of the parents. Acquired traits are not passed on.

Polio is a virus which infects, paralyzes, and is cleared by the immune system. Any stigmata, a weak leg for instance, is an acquired trait and cannot be passed to children. Amputees have normal children, and so do people who had polio. Poliovirus does its damage over a period of about 2 weeks by multiplying, damaging, and killing motor neurons inside the Central Nervous System (CNS). Then fever breaks, antibodies and the immune system prevail, and patients are no longer infectious, although they do excrete poliovirus for a month or so from the lymphatic tissue of the gut. Clearly, the titer and quality of excreted virus is below the infectious dose for passing a damaging infection to others. And the infected, not their children, must live with the acquired damage incurred to the CNS.

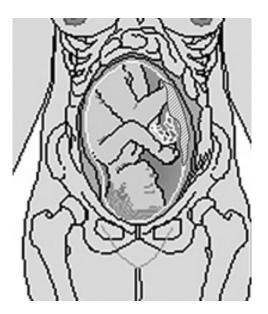
A brain-blood barrier protects the CNS, so even if one accepts an infective theory of PPS, that is, a theory where remaining mutant virus is activated within the spinal cord, blood separation would obviate any way to infect offspring. After a mother recovered from polio, she couldn't infect anyone else. And we don't know for sure if virus is what causes PPS.

Polio, we know, because of the meticulous studies of Sabin

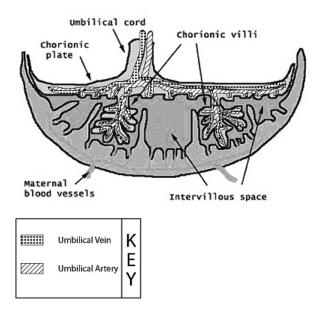
and Bodian in the 1940's and 1950's, enters into the body orally and exits in feces. It grows in the lymphatic tissue of the intestine and sometimes spills over into the blood causing a viremia (virus in blood). This situation can result in paralytic polio by virus migration through nerves into the CNS or by virus moving into the CNS through blood.

Figures 1 and 2 show a drawing of a woman carrying her fetus and a detailed cartoon of the placenta. The umbilical cord is attached to the placenta. Blood from the mother does not mix with blood from the fetus, so here we have a maternal blood/fetal blood barrier and the kinds of viruses which damage the fetus usually grow on or in the cord or on the membranes of the placenta. Such viruses as Rubella, or German measles, are the most commonly known. Other viruses, and there are a few, have a "tissue affinity" for the umbilical cord or the placenta, most likely because those tissues have receptors for the virus.

Blood circulates through the cord to the placenta, an organ with two layers of folded cells which separates blood of mother and child, the folds increase surface area between mother's blood and fetal blood, so antibodies, nutrients, oxygen, and other substances from the mother can dialyze through the two layers of placental cells to the fetus. Wastes from the fetus: carbon dioxide, urea, and various molecules dialyze across the placenta to the mother. Poliovirus, as will be shown below, does not grow in or dialyze through the placenta. This affords protection to the fetus.



**Figure 1**: Note in Figure 1 the position of the fetus and also the hatch marked buildup of tissue to the right. This is the Placenta. Note the umbilical cord is attached.



**Figure 2**: In Figure 2 we see a cartoon magnified placenta which clearly shows blood entering through the umbilical artery and exiting through the umbilical vein. Note both the separation of blood and also the highly folded nature of the placental villi which increases surface area between bloods.

There have been studies, during the polio epidemics of the last century, on the effect of polio infection in woman during pregnancy. One such study was done in Los Angeles and Illinois as described in a New Mobility article in April, 2001. In this study thousands of women in Los Angeles and Illinois had developed a polio infection while they were pregnant. Not one fetus showed ill effects due to the mother's polio.<sup>1</sup> Other studies have shown that antibodies to polio move freely through the placenta while the polio virus does not. As pregnancy progresses the late fetus has more passive immunity than it had earlier during its fetal development. <sup>2</sup>

A review of the literature on this subject demonstrated that although some fetuses could be found that had polio virus associated with them, the virus did not enter the Central Nervous System of the fetus and there was no paretic damage.<sup>3</sup> It is likely that something went catastrophically wrong in such cases. Perhaps a damaged or malformed placenta was present or the mother was not immunocompetent.<sup>1</sup>

In the first 56 years of the past century when polio was epidemic, and add to that 3 years from the end of the 1800's, there were 150 incidences of poliomyelitis reported in children who were under 6 months old.<sup>1</sup> Included with these babies were 4 who were born with a limb paralyzed. So it is clear that contracting polio in the womb, through the placental barrier, is a miniscule risk. On the other hand, the same cannot be said about a mother who has polio.

Pregnant women who develop polio during pregnancy are

5 times more likely to die, although, consistent with the information above; the rate of miscarriage was no greater than that of a normal pregnancy.<sup>1</sup>

The Sabin oral polio vaccine confers active immunity by delivering 3 live polio strains, weakened, to grow in the gut of the vaccinated. There have been a number of studies that have demonstrated the safety of giving this live vaccine to pregnant women. <sup>4 2</sup> These data further bolster the observation that despite the lack of immune competence in an early fetus, live polio vaccine has not resulted in an infection or damage to a fetus.

Therefore, all of the scientific work done on this topic for over a hundred years, puts the idea that a polio infection, contracted in-utero could give rise to Post-Polio Syndrome, as so unlikely that to worry about this in retrospect is foolish. The question has been settled and may be safely set aside. Further, it would seem irrational to lay middle aged complaints, aches and pains, or even more serious medical problems, of those who never had polio, at the doorstep of PPS. This syndrome is a serious concern to those who have categorically been infected with polio and are seeking to have it more seriously addressed by medical systems around the world.

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#### Editor's Note: Additional resources:

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#### About the Author



Edward P. Bollenbach, BA, MA, Professor Emeritus in Biology, Northwestern Connecticut Community College, Winsted, Connecticut.

Known on most of the Internet post polio discussion lists simply as Eddie, he is a polio survivor who has a reputation as a clear and incisive thinker and a prolific writer.

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Topic suggested by Lorraine Frew to Wanda Clas.



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Shining Light on Post-Polio Health

CEPSA's next meeting is on Saturday, October 26, 2013 10:30 AM at The Exchange on Waters 6710 Waters Avenue Savannah, GA 31406

# **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:

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

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

23 East 61st Street, Savannah, GA 31405.

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Are you a relative or friend of a CEPS	SA member?			
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Thank you for your support and a	encouragement.			