

APPA NEWS

The Atlanta Post-Polio Association

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POLIO GLOBAL
ERADICATION
INITIATIVE

every last child

Wednesday, July 31, 2013

Behind the news: the outbreak in the Horn of Africa

Despite the outbreak, the end of polio remains in sight

31 July 2013- A polio-free world is closer than ever to becoming a reality, despite the current outbreak affecting the Horn of Africa which, as of today, has paralysed 105 children.

Reading the news lately, you'd be forgiven for thinking that the outbreak spells disaster for the programme – but don't be misled.

“Before these cases in the Horn of Africa, the end of the multibillion-dollar effort appeared to be in sight,” reported National Public Radio last week in the US.

“The Somali outbreak is now forcing UNICEF, the WHO and other international agencies to dedicate vast resources to boost polio vaccination coverage throughout East Africa and parts of the Middle East. Those are resources that can't be used to attack the virus in Afghanistan, Pakistan and Nigeria — which appeared, until now, to be the last few places where polio

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WEBSITE ADDRESS: www.atlantapostpolio.com

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Message From The President

I'm turning into my dad. Little by little I'm realizing it. That's not in any way a bad thing. When he retired he spent endless hours trying to figure out how to feed birds without feeding squirrels and chipmunks too. We chuckled at his trials and tribulations battlin' our furry friends. Now, fast forward 30 years or so and here I am playing the same game. I've even established a relationship of sorts with them. They are getting so tame they eat off the table inches from me. I have, for the moment, developed a feeder they can't get into. No small feat, including spending time in my workshop cutting, drilling, planning, and contriving, using many of the mechanical skills I learned from my dad. I remember when he died I spent some quiet moments downstairs in his garage thinking about the times we shared there. Looking at the myriad of projects he had in process or in the queue it occurred to me, in that moment, that we never get it all done, do we? If he'd lived to 100 there would still be projects left to do. Now I look around my own garage and the same reality strikes me. In addition, Post-Polio Syndrome, PPS, is slowing me down to the point it's even worse in my case. I wrote about projects last year in this column and reflecting back on that makes me realize the decline I've experienced since then. This is a progressive disorder and I can now see the progression clearly. It used to be I had 4-5 productive hours. Now some days, not nearly that many. It's depressing. I've found something that helps though. I'm learning to modify my expectations. Instead of feeling bad because some project isn't done yet, I just take solace in the fact I made some small amount of progress on it. I try not to anticipate how long something will or should take. Things will get done in their own time and I try to approach a project more as a hobby than a job. What's the difference between a hobby and a job? With a hobby you don't have target dates to meet! It's important for us to understand that concept. Since day one of being editor of [APPA NEWS](#), I followed the philosophy that "we get done what we can when we can." I'm applying that to the rest of my life as well. There seems to be more and more decline among Post-Polio folks. I got some sad news the other day about another Polio support group closing up shop. The First Coast Post Polio Support Group, in Jacksonville, FL. I suppose that'll happen to every group eventually. Either there won't be anybody left to support or there won't be enough energy left in any of us to continue. It's not like we've got a whole new generation of young "whippersnappers" coming along to replace us. That's a good thing, of course, but there will be an end to all of this. I have always disliked the phrase "It is what it is" but I've come to terms with it by understanding that also "It isn't what it isn't." Yeah, I know, that's some kinda double negative that'll drive the proofreaders nuts. For a long time I knew about PPS but lived in denial about what was happening to me. A big step in being able to deal with it has been ac-

Continued on the next page

cepting it for what it is. It's not the end of all activity it's a modification of same. When I'm having one of those days or just "run out of gas" around noon I try and allow myself to just "be done with it" for the day. I look at it like I'm getting back the time when I put in one of those "all nighters" or 18 hour days years ago. I'm not being lazy I'm a PPS'er. Like my mom used to say, "Joey, tomorrow is another day." Even if it isn't I'll still have a garage full of projects yet to get finished...just like my dad.



My buddy "Shorty"
Dad would be so proud. 😊

Joe Drogan - **APPA** President

From the Editor

Words...words...words. Looking over this edition it occurred to me there are a lot of words in this one. Hope you like to read. I probably should have saved some for the winter edition when you're stuck inside and have copious amounts of time for reading. I sometimes get off easy, like the holiday party issue where there's a lot more photo editing and less words, words, words. They are good words, though. I wanted to report on at least one of our recent book reports and was pleasantly surprised when Barbara Mayer not only provided me with notes from her report but wrote an excellent article I was able to use "as is." I surmise by the quality of her writing that she was one of those kids back in school that got straight "A's" in English. This, of course, while I was either snoozing or thinking about my girlfriend and the upcoming weekend. Well, in my defense, if I knew then I'd wind up being an editor about 50 years later I'd have paid a little more attention. Among the superfluity of words there are articles on the current polio outbreak in Africa, the devastating effects of Bulbar polio, and a great knowledge resource at The Polio Outreach of Washington. There is advice for you from Tech Bits and Bytes about your "pocket" computer, otherwise known as your cell phone. They say the PC is dead, being replaced by the cell phone and tablet. There are writers that refuse to abandon their old Remington typewriters, will I be the last guy out there using a PC to produce a publication. I'm not so sure I won't. I can't type a lick on one of those on-screen keyboards. I've only got a few fingers that work well enough to type on a "real" keyboard. Maybe using voice activated typing. Hey, that may be a good topic on accessibility for an upcoming Tech Bits & Bytes. So get comfy and plan to spend some time reading.

Joe Drogan

Continued from page 1
had a foothold.”

This is not entirely the case. [The Washington Post](#) explains, “the outbreak is not likely to derail the global campaign for eradication.”

“Until polio transmission is interrupted in the endemic countries, outbreaks such as the one in Somalia are to be expected,” explains Dr Hamid Jafari, Director of Polio Research and Operations at the World Health Organization. “So long as the budget for the new Polio Eradication and Endgame Strategic Plan is fully funded, we’re well-equipped to pursue endemic and outbreak priorities simultaneously.”

The new Strategic Plan is yet to be fully funded. While the funds are in place to deal with the current outbreak, it is important that the rest of the funds are committed if future outbreaks aren’t to pull resources from the incredibly important task of ending polio in the three remaining endemic countries – Afghanistan, Nigeria and Pakistan. Until polio is stopped in these three countries, the global community will have to accept that outbreaks such as the one in Somalia are going to occur.

“This is one of the reasons why we’ve been asking for the funding up front – so that we have the resources to continue our operations in the polio endemic countries and deal with any new outbreaks,” concludes Dr. Jafari.

Related

Anticipating outbreaks on the path to eradication - See more at: <http://www.polioeradication.org/Mediaroom/Newsstories/Newsstories2013/tabid/488/iid/318/Default.aspx#sthash.3sTCgwpd.dpuf>

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Thanks.

APPA NEWS

**APPA wishes to thank the following
for their donations.**

**Patricia Emerson
Jane Kilgore
Robert Urie**

Thank You!!!!!!

HELP WANTED

The New APPA Resource Database

APPA is starting to collect information on resources our members have found useful. This would include, but is not limited to, information on polio doctors, brace makers, and power chairs. Clarence Weaver has graciously offered to maintain this database for us. We are in the process of determining what form the database should take. It most likely will be an Microsoft Word document that could contain email addresses and website hyperlinks and would be accessible by the majority of our membership. Our plans include putting it on the **APPA** website as well. Printed copies will be available upon request.

This is the part where we need your help!

Please send us any information that you think would be helpful.

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Polio Outreach of Washington

POST POLIO SYNDROME: LIVING WITH THE LATE EFFECTS OF POLIO

<http://www.poliooutreach.com/index.html>

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By Joe Drogan

Every now and again I run across a website, other than **APPA**'s fine site, that is of particular interest to us. This is one of those sites. I happened along here researching Bulbar polio for this edition of **APPA NEWS**. Not only did I find a great article by a Dr. Henry, but a wealth of information about Post-Polio. Everything from **A** to **V**, Alternative Medicine to Vision. I contacted their president, Stan Barber, for permission to reprint the article about Bulbar polio and was not only given that permission but we are allowed to use anything from the site. I tried to screen shot the resource listing page to allow you to see what is available there, but it was hard to fit it on a printed page large enough to read. (see page 11). You really should pay the site a visit. The organization is a combination of 12 support groups in the state and has many resources to draw upon. They send out 2,000 mailed copies and 300 emailed copies of their newsletter. The production department here at **APPA NEWS** gets dizzy just thinking about that! They have Dr. Henry, who has written many articles about various aspects of Post-Polio. I have included one here so you can get a feel for the content on the site. They even have a section on Relationships and Sex. The **APPA** censors get nervous just by just me mentioning that! Take a look at the site, I'm sure you will find a wealth of information there.

Dr. Henry writes about Bulbar and spinal polio

Bulbar polio involved the brain stem where the centers for the cranial nerves are located. The cranial nerves involve smell (olfactory), vision (optic), three cranial nerves control the various muscles that control eyeball movements, the trigeminal nerve and facial nerve which innervate cheeks, tears, gums, and muscles of the face, etc, the auditory nerve which provides hearing, the glossopharyngeal nerve which controls in part swallowing, and functions in the throat, another cranial nerve which controls tongue movement and taste and one that actually sends signals to the heart, intestines, respiratory (lungs) and

Continued on the next page

the accessory nerve that controls upper neck movement. Thus bulbar polio could affect any or all of these functions. Death from bulbar usually occurred from damage to the cranial nerve sending the signal to breathe to the lungs. This nerve stimulates our breathing during sleep. An iron lung, invented around 1926 could keep victims alive with negative pressure breathing. Today, ventilators mostly utilize positive pressure breathing because it is more efficient. Bulbar victims could also die from damage to the swallowing function because a victim could drown in their own secretions unless adequately suctioned or given a tracheostomy to suction secretions before the secretions entered the lungs. It was difficult to have a tracheostomy and still be able to tolerate the air tight collar of an iron lung. Death also occurred from the overwhelming invasion of the virus into other parts of the brain causing coma and death. This was found on autopsy in some deceased victims.

Spinal polio involved damage to the anterior horn cells which run up and down the spinal cord. These cells control motor function only. Sensory cells in the spinal cord were spared, thus we all feel pain and touch. Paraplegics and quadriplegics do not have motor or sensory function below the level of their injury. Spinal polio could damage the muscles of breathing in the chest wall and thus spinal polio victims could also need the assistance of a ventilator or iron lung. Many people had both, spinal and bulbar combined. Actually, many victims that had bulbar alone and had good recoveries had good muscular function because their spinal cord was not involved. With PPS, many of these people are having swallowing and central fatigue problems or problems with any functions related to the cranial nerves (double vision for example).

I hope I am explaining this adequately. Statistically, most of us had spinal polio, and most that had bulbar had it combined with spinal. But now we seem to be learning that many of us had brain involvement during the acute infection that did not do any recognizable damage then, but may be giving us problems now with the total body fatigue or central fatigue of PPS.

People who had only the GI form of polio which we had initially when we became ill (flu like) had the non-paralytic type of polio. The mystery now is whether these people may have had silent CNS involvement and are subject to PPS.

This disease, back before Salk and Sabin, and now with PPS, is amazing and fasci-

nating to any one who studies the natural course of infectious diseases that do not always kill you quickly. Syphilis was this way before antibiotics and Aids is similarly tragic and fascinating in its specificity for the cells of the immune system. Viruses are wonders of nature. I wished I had missed this one in 1950.

Take care all and I love this service to each other.

Henry Holland, Richmond., Virginia, USA. Henry4FDR@aol.com

21st February 1997

Addendum

Yesterday, I posted from memory my thoughts on bulbar and spinal polio as well as spinal/bulbar polio. What is posted is generally correct. However, I got out my neurology text and will give some specifics since the readers on this list are learned folks and like accuracy.

The twelve cranial nerves and their functions are:

1. Olfactory nerves (2) to transmit the sensation of smell to the brain.
2. Optic nerves (2) to transmit visual information from the eye to the brain.
3. Ocular moto nerver (2) supply the pupil constrictor function, eyelid function, abductor and elevator muscles of the eye.
4. Trochlear nerves (2) supply the superior oblique muscle of the eye, turning eye inward when the eye is adducted.
5. Trigeminal nerves (2) provide sensory innervation of the face, motor supply to the jaw muscles, and the sensory innervation of the cornea providing for the corneal reflex.
6. Abducens nerves (2) supply the lateral rectus muscle of the eye, the ability to turn the eye to the side.
7. Facial nerves (2) supply motor function of facial muscles (facial expression) and provides taste for anterior 2/3 of the tongue.
8. Acoustic nerves (2) provides two functions, one is hearing or auditory and the other is the vestibular function which transmits impulses to monitor equilibrium, orientation in space and changing position. Spinning fast may produce dizziness.
9. Glossopharyngeal nerves (2) The 9, 10, and 11th nerves work together to provide for the muscles of swallowing, speech, and taste (for posterior 1/3 of the tongue). They also innervate the muscles of

the palate and part of the tongue.

10. Vagus nerves (2)
11. Accessory nerves (2)
12. Hypoglossal nerves (2) innervate ipsilateral tongue muscles, and allow the protrusion of the tongue out of the mouth on a midline.

Many of these nerves have branches, especially the trigeminal and vagus. The "bulb" or medulla part of the brain contains the ascending corticospinal tracts of the spinal cord, the descending sensory tracts of the spinal cord and the nuclei of the 9th thru the 12th cranial nerves. Thus, bulbar polio would most commonly affect the 9th thru 12th cranial nerve and could also affect the anterior horn cells in the spinal cord causing motor paralysis or damage to the muscles being supplied by those spinal nerves. Usually the damage was asymmetrical and could even be upside down (a person left with the ability to walk, but possibly in need of a ventilator). Thus more often bulbar polio involved problems with swallowing, breathing and speech. Add the spinal component and there would be motor paralysis, as severe as quadriplegia of motor function, not sensory.

Most people had nonparalytic polio, followed by spinal, followed by spinal-bulbar. Now I think since other areas of the brain were also involved even in spinal alone, there is some rationale as to why so many of us are now experiencing central fatigue as a symptom of PPS. So much of the central nervous system may have been involved unknown to us and our doctors at the time. The doctors, nurses, and physical therapists could only record and measure the observable losses during the time periods of the polio epidemics, not the unobservable damage. I think this explains in part at least part of the mystery of why we are experiencing such a variety of signs and symptoms with PPS. At least it makes a little bit of sense to me. I hope I communicated this in a readable manner.

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Thank you,
APPA NEWS

Alternative Medicine

You Are What You Eat
Tai Chi
The Benefits of Massage
What Is Acupuncture?
Post Polio Syndrome and Chiropractic

Anesthesia

Anesthesia Concerns for the Polio Survivor
Swallowing Tips
The Knife Is Not So Rough

Assistive Device

The Battle with Bracing
Tidbits

Breathing/Pulmonary

Post-Polio Breathing and Sleep Problems
Rx for Fatigue

Caregiving

True Answers for Friends and Families

Dental Care

Polio Patient Dental Precautions

Dietary Issues

Post Polio Institute Hypoglycemia Diet
You Are What You Eat

Exercise

Dr. Perry's General Information Letter for Polio Survivors
Tai Chi
What Are Your Options?
Exercise - What Is Right for You?

Fatigue

Changing Your Life by Conserving Energy
Energy Conservation
Energy Saving Techniques

General Information About Post Polio Syndrome

Salk polio vaccine field trials of 1954
Bouncing Back Without Guilt
Characteristics and Management of Post-polio Syndrome
Cholesterol and PPS
Chronic Illness Bibliography
Changing Your Life by Conserving Energy
Coping Styles of Polio Survivors
Post Polio Personality
Do's and Don'ts for Polio Survivors
Dr. Henry writes about Bulbar and spinal polio

Dr. Henry writes about Hints for Living with Post-Polio Syndrome
Empowering the Polio Survivor
Recognizing the need to adjust your life-style

General Information - A Brief Guide
How to Live Well with Chronic Disease

"Old Polio's" - Dr. Perry
Post Polio Research - New Mobility
Post-polio Syndrome: An Update
Preventing Overuse Is the Key
Recommendations for Former Polio Patients
Scientist at Work

The 10 Commandments of PPS
True Answers for Friends and Families

Ultimate Burnout
Use Your Body Efficiently

The Late Effects of Polio
L-Carnitine and Post-Polio Syndrome

Polio ... More Than Once
Polio In Perspective For 1995
Post-Polio Research Update

Post-Polio Symptoms & Effects
Acute Anterior Poliomyelitis, Some Observations

An Approach to the Patient with Suspected Post Polio Syndrome

A Pound of Prevention Is Worth a Ton of Therapy

An Eleven Year Experience Managing Post Polio

GI/Stomach Problems

Medical Diagnostic Procedures

Diagnostic Sono-gram Uses in Post Polio Syndrome Disorders
Dr. Henry writes about spinal taps
EMG Information
Magnetic Resonance Imaging

Medications/Herbal Information

Drug use Cautions for PPS
Take A Look At Estrogen
Why A History of Polio Is Critical
Medications

Pain

Pain in Post Polio Syndrome

Polio and the Onset of PPS

A Ten Year Experience
Do PPS Come After A Fall?
Non-Paralytic Polio As Prelude to PPS
Polio After Effects Challenge Solence
Polio Survivors
Polio, Strains and History

Polio Encephalitis

Explaining Post Polio Fatigue
Changing Your Life by Conserving Energy
Energy Conservation
Energy Saving Techniques
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Post Polio Myelitis Fatigue: Where Is the Lesion
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Rehab/OT-PT

Approach to the House
Dr. Perry's General Information Letter for Polio Survivors
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Occupational Therapy—Energy Conservation For Post-Polio
Physical Therapy for PPS Patients

Relationships/Sex

PPS and Intimacy
Preserving and Strengthening Interpersonal Relationships
Sex and Polio Survivors

Sleep/Apnea

Post-Polio Breathing and Sleep Problems
Sleep Apnea

Social Security Disability

Applying for SSD
Disability
Getting Social Security Benefits
2001 changes SOCIAL SECURITY

Stress/Coping

Bouncing Back Without Guilt
Contribution of Childhood Trauma
Depression & Persons with a Disability
Emotional Stress In Polio Survivors and PPS
How Healthy Is Your Esteem?
Managing Stress and Anger
Recognizing Typical Coping Styles of Polio Survivors Can Improve Rehabilitation
The Hassles of Living with PPS
Learning to Manage Stress

Swallowing

A Review of Swallowing Difficulties In Post Polio Individuals
Dysphagia
Swallowing
Swallowing Abnormalities

Urinary Incontinence

Age Page - Urinary Incontinence
Dr. Henry Writes: About Urogenital Problems & PPS

Vision

Dr. Henry writes about Bulbar and spinal polio

APPA Meeting Insider

By Joe Drogan

It occurred to me the other day, driving home from the **APPA** meeting, that we don't have huge attendance at our monthly meetings. More and more of us are experiencing health issues, scheduling problems or just finding it more and more of a hassle travelling. I thought an occasional column talking about what went on at the meetings might be a welcome addition to [APPA NEWS](#).

So here is what you missed if you couldn't attend.

The meeting occurred on Saturday August 3, 2013, at the usual IPM at Shepherd Center. Some of us met beforehand for a quick lunch in the cafeteria. The food is good, reasonably priced, and fairly healthy. It's a hospital so, you know, go figure. Please consider joining us before some meeting in the future. When we arrived up stairs at the auditorium the room was set up with the incredibly uncomfortable "white" folding chairs. We decided to set up in the adjoining smaller room adjacent to the auditorium. It has a nice view of Atlanta and is great for a smaller group. We had 12 in attendance. Including a new member Juliane Kilgore. Welcome Juliane!

After a little confusion, our post office box was renewed for another year; just so you know, a PO Box renewal is called "Your Caller Service Fee Payment." Who knew? We are all squared away with required reporting to the IRS for 2012. We are required to submit a form 990-N to insure continuation of our 501(c3) non-profit status. We will be sending a second change of address notice to some polio groups that are still sending things to our old PO box. Forwarding ends this month. The annual Dues Reminder letter will be going out this month. The question has come up as to whether or not we should put links to non-polio related sites on our website. It was discussed and the consensus was that we should keep our site only polio-related. So you won't be seeing a link to "Penguin Support Groups in the USA" anytime soon.

The main meeting was followed by the following book reports:

[Barbara Mayer](#) - "[A Paralyzing Fear, The Triumph Over Polio in America](#)" by Seavey, Smith, and Wagner

[Shannon Morgan](#) - "[Warm Springs: Traces of a childhood at FDR's polio Haven](#)" by Susan Richards Shreve

["Small Steps: The year I got Polio"](#) by Peg Kehret

[Calvin State](#) - "[Dr. Mary's Monkey](#)" by Edward T. Haslam (learn about the strange connection with the JFK assassination!)

["Me & Lee"](#) by Judyth Vary Baker

One lesson learned during the meeting was that there isn't enough time during a meeting for any more than one, perhaps two, book reports.



Di\$count\$



APPA NEWS knows times are still tough!

We are pleased to present you with the new and updated **Discount List!**
In this issue we have **Restaurant Discounts** for you.

RESTAURANTS:

Applebee's: 15% off with Golden Apple Card (60+)

Arby's: 10% off (55 +)

Ben & Jerry's: 10% off (60+)

Bennigan's: discount varies by location (60+)

Bob's Big Boy: discount varies by location (60+)

Boston Market: 10% off (65+)

Burger King: 10% off (60+)

Chick-Fil-A: 10% off or free small drink or coffee (55+)

Chili's: 10% off (55+)

CiCi's Pizza: 10% off (60+)

Denny's: 10% off, 20% off for AARP members (55 +)

Dunkin' Donuts: 10% off or free coffee (55+)

Einstein's Bagels: 10% off baker's dozen of bagels (60+)

Fuddrucker's: 10% off any senior platter (55+)

Gatti's Pizza: 10% off (60+)

Golden Corral: 10% off (60+)

Hardee's: \$0.33 beverages everyday (65+)

IHOP: 10% off (55+)

Jack in the Box: up to 20% off (55+)

KFC: free small drink with any meal (55+)

Krispy Kreme: 10% off (50+)

Long John Silver's: various discounts at locations (55+)

McDonald's: discounts on coffee everyday (55+)

Mrs. Fields: 10% off at participating locations (60+)

Shoney's: 10% off

Sonic: 10% off or free beverage (60+)

Steak 'n Shake: 10% off every Monday & Tuesday (50+)

Editor's note:

Many thanks to Cathy McIntire for sending me this new list, allowing the Discount list feature to continue. Much appreciated as it makes a nice informative feature in APPA NEWS that doesn't require a whole lot of deep thinking on my part! 😊

Continued on the next page

Thoughts

by Myrna K. Whittington

A Potpourri of Life

It seems that the predominant color for fall is green, which just fits in with our life style of being green.. I do not know about other folks but I am right in style. When I look in the mirror there is this definite tinge of Green, yikes, I am turning moldy!! The worst thing is that I am allergic to mold. Can it be I am allergic to myself?

Mother Nature is very mean, when the forecast is for pop-up, SLOW moving showers, she has a HUGE arrow pointing directly at Stone Mountain, GA we have not been missed yet!! Hence the color Green on my skin.

But the good news is, that maybe in winter I'll be yellow?

Myrna Whittington

Continued from the previous page

Subway: 10% off (60+)

Sweet Tomatoes: 10% off (62+)

Taco Bell : 5% off; free beverages for seniors (65+)

TCBY: 10% off (55+)

Tea Room Cafe: 10% off (50+)

Village Inn: 10% off (60+)

Waffle House: 10% off every Monday (60+)

Wendy's: 10% off (55 +)

Whataburger: 10% off (62+)

White Castle: 10% off (62+) This is for me ... if I ever see one again.



The information provided herein represents what the authors believe they heard during presentations at APPA. The authors are neither legally or medically trained and for these reasons may not have recorded an accurate accounting or understanding of the important details discussed. Neither they nor APPA assume any responsibility for the accuracy of the information provided. It is, therefore, highly recommended that all and any information provided be confirmed with an appropriate lawyer or physician before applying any of these legal instruments or medical treatments on your own. It is hoped that this summary serves to apprise the reader of available means to help them be prepared for the future.

APPA BOOK REPORT

By **Barbara Mayer**

A Paralyzing Fear

The Triumph Over Polio in America

Written by:

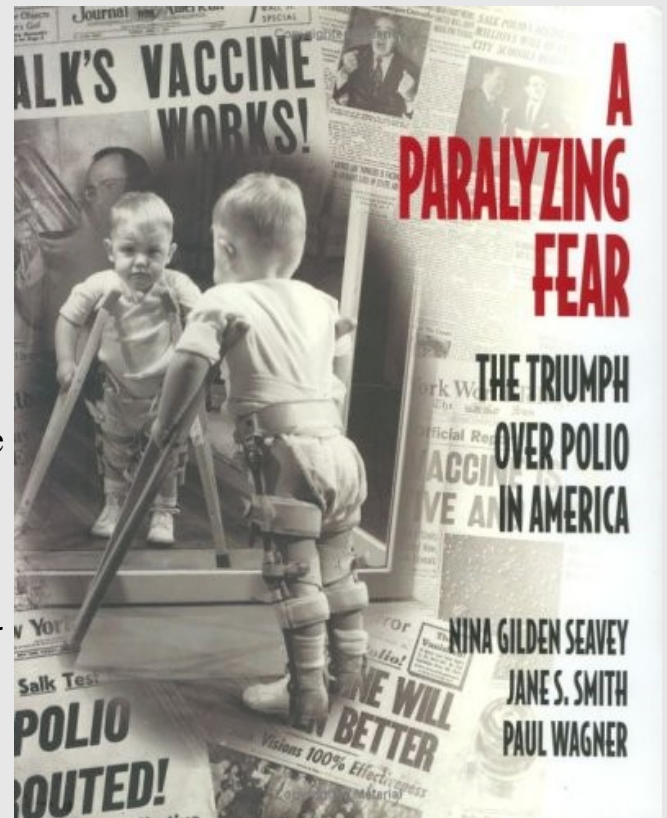
Nina Gilden Seavey – director & producer of the film “A Paralyzing Fear,” is Director of the Center for History in the Media at The George Washington University in Washington D.C.

Jane S. Smith – author of *Patenting the Sun: Polio and the Salk Vaccine*, lives in Chicago

Paul Wagner – producer of the film, won both the Academy Award & the Emmy Award for his documentary “The Stone Carvers,” lives in Charlottesville, VA

Published in 1998.

This book not only documents the history of polio in America and the search for a cure, but is a testimony to America’s collective commitment to triumph over one of its most terrifying epidemics. Seldom in history has a society completed the full cycle of disease – from illness to epidemic to cure. The story of polio tells how fear changed America. For over 50 yrs, no one could predict where or when the next epidemic would strike. In the beginning, no one knew what it was, or how it spread, or why it had arrived to attack the youngest part of the population. No one could tell who would be hurt. Polio broke America’s heart. The first response to the disease was **panic and a paralyzing fear**. Polio could kill but the real terror was the number of paralyzed victims who lived. Hospitals refused to treat the sick, neighbors fled from neighbors, schools and theaters closed for fear of contagion, ignorant doctors offered treatments that turned out to do more harm than good, and unscrupulous quacks profited from the desperation born from fear. In the end this story is a record of a triumphant national mobilization in a common cause, and of ordinary people caught up, most painfully, in extraordinary times.



Continued on the next page

The book has 6 chapters that review the history of polio and at the end of each chapter is a section called “**Voices,**” where doctors, nurses, polio survivors, and people associated with the March of Dimes were interviewed. In total, 25 people were interviewed.

Chapter 1 – New York, NY 1916

Americans were confident that they lived in a time and place where opportunities were vast and individuals could shape their own destinies. People believed that science and technology would lead to the conquest of disease. Civil engineers were creating a network of aqueducts and water purification plants to provide clean, safe drinking water for much of the nation. Vaccines had been developed for cholera, tetanus, diphtheria, and rabies. There was an increase in sanitation, nutrition, hygiene, and infant and child care.

In the summer of 1916, tragedy struck. A mysterious epidemic began in New York City and spread from there. Dozens, then hundreds, and then thousands of children were taken ill. By mid-August, almost 9,000 victims had been reported in the mid-Atlantic states. Better sanitation in the home and community had steadily driven down the diseases like typhoid, dysentery, and TB. NY officials doused the streets with 4 million gallons of water a day, and killed 72,000 stray cats.

Decades would pass before researchers began to realize that polio epidemics were an ironic consequence of better sanitation, which kept infants from the early, mild infections that had generally conferred immunity in the past.

When summer passed, the temperature dropped and so did the polio epidemic. By the end of 1916, 27,000 cases had been reported in 26 states. 80% of the victims were children under 5 years old. Epidemiologists now estimate that only 1% of polio cases led to paralysis.

The terrors of the 1916 polio epidemic were quickly replaced by WWI and the staggering death toll (over 600,000 in US alone) of the influenza pandemic of 1918. But unlike the victims of war or influenza, most polio victims survived, but with some degree of paralysis. At that time, there were few provisions for their care. The world was unprepared for a sudden generation of crippled children.

Chapter 2 – FDR and the Transformation of Polio

FDR contracted polio in Aug 1921. He would spend the next 7 yrs devoting most of his time and energy, and a good deal of his personal fortune, on efforts to regain the use of his legs. In 1924, a friend suggested that FDR visit Warm Springs, GA, where there was a thermal spa for the well-to-do, whose waters were rumored to “cure” paralysis. Obviously, the waters did not end his paralysis, but the exercises that FDR did in the water help build up other muscles and made him feel better. FDR spent over ½ his personal fortune to buy the property in 1926.

As history’s most prominent and charismatic “polio”, FDR did more than any other person to change the popular image of the disease from something shameful and dirty to what it was: a sometimes debilitating infection that could, and did, strike anyone. The public began to learn to not define people by their disability.

Chapter 3 – Politics, Hollywood, and Money

When FDR left Warm Springs in 1928 to campaign for Governor of NY and then for the presidency in 1932. He handed the management of the therapy center to his law partner, Basil O'Connor. O'Connor made Warm Springs resort into a nonprofit foundation, raising \$\$ from wealthy patients, their families, and friends. It became clear that even this would not provide enough \$. When FDR was elected president, O'Connor began to use the prestige of the presidency to serve his new cause. The GA Warm Springs Foundation was joined by the National Foundation for Infantile Paralysis which led to national fundraising. The first campaign was a series of nationwide annual balls at the end of January (FDR's birthday) with the slogan "dance so that others may walk." Mostly the rich and famous attended these balls, but after 6 yrs, the \$\$ raised started to dwindle but the costs of caring for polio patients continued to rise. In 1938, Eddie Cantor suggested a new sort of charity appeal and he coined the name "The March of Dimes" which was wordplay on the popular contemporary newsreel series "The March of Time." Now every citizen was called upon to work for the common good. You didn't need to be rich, anyone could give a dime. \$\$ was raised from local chapters and the national headquarters financed the care of patients including purchasing equipment, gave scholarships to nurses and doctors who needed training, and funded lab research.

Hollywood stars from Mickey Rooney to Greer Garson, Danny Kay, Bing Crosby, to Elvis Presley aired appeals in movie theaters, on radio, and later on TV.

WWII brought another change to the war on polio. Women were enlisted to take the place of the male fundraisers who had gone to war, and a new emphasis on polio as a family issue dominated the March of Dimes campaigns – we must protect our children.

In 1946, the March of Dimes Poster child was introduced as another fundraising innovation. At the time, this was a radical idea. Poster children were cute and attractive and they used braces and crutches. The children did not look pathetic. Some feel that this exploited and manipulated kids, but the cause was worthy and it worked.

Chapter 4 – The Polio Patient

This chapter talked a lot about iron lungs and how they were both a prison and salvation for the patients who needed them.

In the 30s, with no clear knowledge of how polio was contracted or how the virus caused paralysis, MDs tried almost anything. Patients were injected with the smallpox vaccine, adrenaline, horse, sheep, goat, and monkey serum, strep serum, their own spinal fluid, their own blood, their parents' blood, serum from recovered polio patients, and anything else. Of course, none of that worked. Most patients were completely immobilized during the acute infection phase. Months of bed rest and then massage was prescribed. In 1940, Sister Kenny, nurse from Australia, insisted all of the American experts were wrong and she developed her own program which consisted of hot packs and massage early in the disease process. This treatment produced better results and soon, immobilization was abandoned.

African-American children contracted polio just as often as white children, but in the South, due to segregation, they were not allowed to go to Warm Springs. The National Foun-

dation funded the Infantile Paralysis Center at Tuskegee Institute in Alabama.

Chapter 5 – Salk, Sabin, and the Search for a Vaccine

In 1905, MDs realized that polio was an infectious disease. Suggested, at that time, that person-to-person contact spread the disease. In 1908, Karl Landsteiner showed that monkeys could be infected with polio.

Early on, scientists postulated that polio was caused by something smaller than bacteria (which could be seen under a microscope) because the virus could not be detected. The virus was finally seen in the 1930s thru the development of the electron microscope.

In 1935, before it was known that there were 3 different types of polio virus or even that the virus circulated in the bloodstream, Dr. John Kolmer designed a vaccine that he believed would give immunity to polio, using a weakened strain of polio virus obtained from the spinal columns of paralyzed monkeys. The results were disastrous – some children were paralyzed and some died.

During WWII, polio became another front of the war. Albert Sabin, already established as a virologist and an authority on polio, joined the Army Medical Corps and was assigned to the Middle East, where polio had mysteriously broken out among Allied troops, but few children in North Africa or around the Mediterranean, ever contacted polio. Sabin discovered that polio virus was endemic in the area, but that most children became immune thru exposure in infancy when they were still protected by antibodies they received from their mothers.

All along, vaccine research meant infecting and the dissecting monkey after monkey. Finally, in 1948, when John Enders and his colleagues, discovered how to grow polio virus in test tubes, using a broth made of monkey kidney. Next, came the need to identify all strains of the polio virus.

In the 1950s, the push toward prevention was further complicated by passionate arguments about whether the best vaccine would be made from inactivated or “killed” virus, or from attenuated live virus.

The leading proponent of the killed-virus was Jonas Salk and Albert Sabin believed the best vaccine would come from a live attenuated virus. Sabin believed a killed-virus vaccine would not provide long lasting immunity.

In 1952, there 59,000 cases of polio in USA. By then, polio epidemics were 2nd only to the atomic bomb in surveys of what Americans feared most. Epidemics struck other countries, but never as heavily as here.

In the spring of 1952, after 2 yrs of preparation, Salk went to a nearby institution devoted to the rehab of crippled children, and gave the patients his vaccine. Then he drew blood to see if the children’s antibodies had increased. (No one knew that Salk was performing this trial until he presented the results at a national conference in 1953.) During 1953, Salk expanded his local tests to subjects who had not had polio with entirely safe results. The National Foundation advisors debated moving to a massive field trial with children from all over the country. Salk’s killed-virus vaccine was tested on 1.8 million school children in the spring and summer of 1954. Some received the vaccine, some a placebo, and some served as ob-

served controls. 20,000 MDs, 40,000 nurses, 50,000 teachers, and 200,000 other volunteers helped with trial. Then at 10am, on April 12, 1955, the 10th anniversary of the death of FDR, it was announced that the Salk vaccine was safe and effective. Nationwide vaccination began immediately.

2 weeks into nationwide vaccination, some children who had received the Salk vaccine, came down with polio. It was discovered that the Cutter Laboratories in California did not follow all of the production guidelines, and vaccine from that lab was contaminated with live polio virus. 204 vaccinated children, their siblings, and their playmates had contracted the disease. 50 kids were paralyzed and 11 died. The problem was corrected and vaccination continued.

Within 2 years of the introduction of the Salk vaccine, polio incidence dropped by 80% in areas where everyone was vaccinated, but some people weren't getting vaccinated. People felt safe again and didn't think the vaccine was necessary, also the vaccination required 3 separate injections.

By 1959, Albert Sabin was ready to test his live attenuated virus vaccine, which was taken orally. For a successful test, he needed a population that hadn't been vaccinated, so he went to Russia. In the next 2 years, 77 million Russians took the Sabin vaccine. The test was judged a success by world health experts and in 1961, the AMA endorsed Sabin's oral polio vaccine. Within 5 years, the oral vaccine, OPV, replaced Salk's vaccine. (But in 2000, the USA went back to the injectable vaccine, IPV. The risk with OPV lies in the secondary risk for transmission of the poliovirus. While there are very few cases of the development of vaccine-associated paralytic poliomyelitis, VAPP, the risk is still present and is not found in the IPV risk.)

Chapter 6 – Polio Survivors and Post-Polio Syndrome

We, at **APPA**, could have written a better chapter, nothing new.

The voices sections after each chapter were very interesting. Many of the polio survivors talked about how difficult their hospitalization was, mainly because many hospitals only allowed parents to visit on Sunday afternoons.

This book covered over 70 yrs of polio history in America – from fear of the unknown to the successful development of not one but two vaccines. I recommend reading this book.

Statement of Policy

APPA and **APPA NEWS** do not express or imply endorsement of physicians, products, seminars or services that are mentioned in this newsletter. They are mentioned simply as a public service to polio survivors and those interested in them.

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Miscellany



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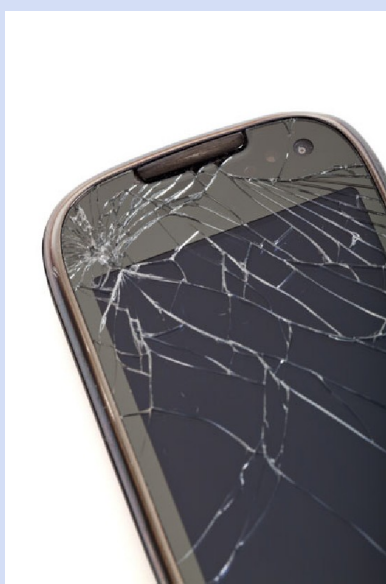
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Photo By:
Joe Droган

**Seen at a local hospital.....Anybody see a problem here?
After some closer inspection I realized...nope the room's still right
there where it always was. 😊**

Tech Bits & Bytes

By Joe Drogan



Yep! It happens to the best of us. Hope you've got cell phone insurance. Cellphone insurance? Really? It seems like every aspect of life requires some form of insurance. My life is insured, my home, cars, boat, and health are too. Even my disability is insured. Good thing too. When I signed up for that initial disability policy nobody had even heard of Post-Polio. Life always been a decision of what to insure and what not to. There was also that period of time where my auto insurance almost made the decision for me to "not be insured." Something about that 145 mph in a 55 ticket didn't impress them all that much. In a perfect world where you have almost too

much money, what the heck, just insure everything to the max and be done with it. However in the real world it's not so easy. One "rule" is to insure against catastrophes. Another way is to evaluate risk as acceptable VS unacceptable. When it comes to cell phone insurance there are a few things to consider. My latest phone is a Samsung Galaxy S4. It retails for around \$600. I got a deal on it thru my carrier as an upgrade but if it had to be replaced I'd be out a pretty penny. I'm pretty easy on equipment and don't tend to loose things, at least not yet anyway. So here's the deal. For right now, even though the coverage is \$11.00/month it's worth it. However, with most cell phone insurance, if they need to give you a replacement phone it will be a "refurbished" unit. (See the insert about "refurbed" equipment.) What I recommend is keeping an eye on the sales of refurbished units. When the cost to buy one equals or is less than the cost per year of the insurance it's probably time to stop paying the insurance. Now keep in mind if you have luck like mine the day after you drop the insurance the darn thing will wind up at the bottom of a vat of tapioca.

Mmmmm.....tapiacoca.....sorry got distracted for a second there. A good way to check on the cost is on EBay. One downside of replacing your phone with or without insurance is the loss of the information stored on it. That is, of course, unless you've backed your phone up to, say, your PC or Mac. That, my friends, is a whole 'nuther topic for a future article. I am totally amazed how

Continued on the next page

people are permanently attached to their cell phone. They have hundreds of contacts, and photos and yet have never backed any of it up.

If you loose your phone it's getting more likely you would get it back. The government is pushing the cell carriers to check for lost or stolen phones before activating them. Your phone has a unique identifier in it used for activating it among other things. There are some things you can do pretty easily to help get your phone back if you do loose it. You can add an ICE or In Case of Emergency, or Owner entry into your contact list. Many people know to look for the ICE entry. If they are trying to find the owner of a phone they found they have a way to try and contact you or someone who knows you. It's helpful to put a dash (-) or underscore (_) in front of the entry name to cause it to show at the top of the list. I have an entry in mine called ME with my home phone in it. I guess it would be kinda dumb to put my cell number there instead 'cause if you find my phone it isn't helpful to call it to try an' reach me! Kinda like locking a spare car key in your glovebox. You can also tape your contact info to the back of the phone but I'd be afraid of it wearing off without being, say, laminated. "If I'm found please return me to....". My memory ain't getting any better. Probably should put a card like that in my wallet. 😊

Hope this helps you protect your cell phone and maybe save you some money. Keep an eye on this space. In the future we'll be talking about cell phone backups.

Refurbished equipment

Refurberd stuff comes in lots of flavors. True factory refurbished units are the best bet. That means if it's, say, an Apple iPhone and reconditioned BY Apple it's usually a better bet than if it's done by some third party. I have bought remanufactured equipment from various sources and have had good luck. This article is, in fact, being written on a refurbished (not by Apple) MacBook that has been rock solid so far. YMMV. Your mileage may vary.

Bonus cell phone tip!

A while back I started doing this. Take off the back cover to your phone. Fold up a \$10, \$20 or \$50 dollar bill and put it inside. Try and fold it as few times as possible to keep it as flat as you can and be sure it doesn't cover the camera lens.

Until next time - **Happy Computing!!!**



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- ☐ I am a new member. ☐ I am renewing my membership.
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APPA 2013 CALENDAR

September 7	"Stretching" presented by Elizabeth Pike, PT, DPT, > Shepherd Center
October 5	Rap Session
November 2	"The Affordable Care Act (aka Obamacare) and Disability" presented by Andy Miller, CEO and Editor of Georgia Health News (GHN)
December	Annual Christmas Party - watch for details.



Atlanta Post-Polio Association

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