Atlanta Post-Polio Association

APPA News

Volume 20, Issue 3 July—September 2007

Inside this issue:

Message From The President

A Day of Celebration in Warm Springs

What a great day July 21, 2007, was for a celebration! The sun was shining, but the weather was cool for a July in Georgia. This was a two-fold day for celebrating at the Georgia Warm Springs Foundation, (AKA Roosevelt Warm Springs Institute for Rehabilitation). We were there to celebrate the culmination of a two-year project to replace the 125 badly deteriorating wooden columns in the historic Quadrangle, and to honor those donors who made it possible. In addition, we were there to celebrate the opening of the newly arrived Smithsonian Institution Exhibit, "Whatever Happened to Polio?"

Those of us who traveled from APPA were happy to be among so many who had come from all over the United States for the event. (See our picture on page 10) There was a Column Dedication Ceremony in the Roosevelt Hall Theater and a reception in Georgia Hall. I have never seen the grounds more beautiful. It was a real treat to see the old place looking so good.

In the afternoon there was a ribbon cutting ceremony for a special showing of the Smithsonian Exhibit currently housed in the Roosevelt Hall Lobby. The exhibit is on loan to us from the National Museum of American History in Washington, D.C. to commemorate the 50th anniversary of the Salk vaccine. Many of the items brought back a flood of memories for me, and I will admit a tear or two. We are fortunate to have the Smithsonian Exhibit in our State.

I encourage you to drive down to see the Exhibit and while there, stop by the newly completed FDR Museum. It is connected to the newly improved grounds of the Little White House. I think you will enjoy seeing all of the attention being paid to polio survivors.

It is important to remember the past, but it is even more important to remind people that "We Are Still Here". Please read about PHI's new initiative We Are Still Here on page 3 in this newsletter. I hope everyone will participate and work hard between now and October to make sure people know that **we *are still here***.

Linda Priest, APPA President

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NEW WEBSITE ADDRESS: www.atlantapostpolio.com

Guidelines for Obstructive Sleep Apnea Patients Established

Selma Harrison Calmes, MD, Olive View/UCLA Medical Center, Sylmar, California

Obstructive sleep apnea (OSA), a relatively common disorder in post-polio people, is now recognized to be associated with increased morbidity and mortality during and after anesthesia and surgery. The American Society of Anesthesiologists (ASA), the national organization for anesthesiologists, approved consensus guidelines on management of OSA patients at its annual 2005 meeting. Although the guidelines' purpose is to focus on which OSA patients might be safely done in an outpatient facility, they are also helpful in planning for OSA patients having surgery in a hospital.

The new guidelines rate a particular OSA patient's risk using a numeric score. A patient with a high score should be treated in a hospital. Rated are the severity of the OSA as determined on a sleep study (or the clinical history if a sleep study is not available), coexisting diseases, invasiveness of the operation, the type of anesthesia needed, anticipated postoperative narcotic requirements and how the patient would be observed post-operatively. The guidelines also define requirements for the facility, such as on-site radiology service for chest X-rays and the ability to do arterial blood gases.

The guidelines also discuss use of CPAP intraoperatively and postoperatively. The need to measure adequacy of ventilation during sedation by continually measuring expired COa (the waste respiratory gas) is emphasized; continuous monitoring of COa is always done during general anesthesia.

The important postoperative period is also discussed. In addition to use of *CPAP,* especially for those on it preoperatively, OSA patients should be monitored for at least 3 hours longer than non-OSA patients. Monitoring should continue for about 7 hours after the last episode of airway obstruction or hypoxemia while the patient is breathing room air and is not stimulated.

Discharge guidelines are also defined. The oxygen saturation on room air should return to baseline, and the patient should not become hypoxic or obstructed when left undisturbed. CPAP use should continue at home for those who used it preoperatively.

The guidelines were developed by a consensus process, using experts in this area and careful analysis of the medical literature. They are not practice standards, do not guarantee a successful outcome and are not yet validated.

Over time, we will learn more about how satisfactory they are and perhaps change them, again using the expert consensus process. However, their development is of great help for those who might be pushed into a procedure at an outpatient facility (a free-standing outsurgery center or even a physician's office) by their insur-ance company. The guidelines can be "ammunition" when fighting the insurance company about where an operation will be done. They are also helpful to anesthesiologists because they help organize thinking about a difficult problem, defining the many factors to consider.

Te September 2005 issue of *Anesthesiology* (Vol. 103, No. 3, pp. 638-644) featured "Postpolio Syndrome and Anesthesia" by David A. Lambert, MD, Elenis Giannouli, MD, and Brian J. Schmidt, MD, from The University of Manitoba, Winnipeg, Canada.

The guidelines are available at
www.asahq.org/
publicatiosandservices/
sleepapneal03105.pdf

POST POLIO HEATH INTERNATIONAL WE'RE STILL HERE Campaign

October 14-20, 2007

Acute poliomyelitis is nearly eradicated worldwide, but **WE'RE STILL HERE.** We - the 20 million survivors living in every country - want the whole world to know of our contributions and needs.

Inspired by the European Polio Union's commitment to an "action day" at the European Union Parliament, Post-Polio Health International calls on all its individual and Association Members worldwide to join the Campaign.

The goal is a "Letter to the Editor" or an "OP-Ed" by a polio survivor, or a radio, TV or Internet interview of a polio survivor in every country, state/province and city/town in the world.

We want to tell the world that:

WE'RE STILL HERE

... working as executives, scholars, teachers, laborers, writers, health professionals.

... attending schools and universities.

... retired but volunteering at schools, places of worship, non-profits.

... anchoring families as parents, grandparents, great-grandparents, siblings.

... committed to enhancing the lives and independence of all survivors of polio.

WE'RE STILL HERE

... needing greater access to education, employment and transportation.

... needing improved access to medical care, including rehabilitation and re-rehabilitation.

... asking for support of the worldwide poliovirus eradication effort, insisting that the appropriate agencies and governments finish the job and maintain appropriate vaccination rates.

What are PHI's objectives?

- To educate about post-polio issues.
- To remind the general public of our successes and contributions.
- To find all survivors, including the oft-forgotten younger ones.
- To recruit health professionals to treat us.
- To initiate a comprehensive secure searchable database.

You Can Help! Join the Campaign. Start now!

PHI has created several sample letters that we will send on request. Go to www.post-polio.org and click on "**WE'RE STILL HERE**" for more ideas as to how you can join the Campaign.

Association Members and Support Groups: Contact your local media to plan for the **WE'RE STILL HERE** Campaign during the week of October 14-20, 2007.

The next *Post-Polio Health* will be published after October 14-20, 2007. Send your published letters to PHI so we can acknowledge them and track the results of our **WE'RE STILL HERE** Campaign.

Introducing Our Newest Board Member - In Her Own Words

Shirley Ann Duhart-Green Fund Raising

Hi, I am Shirley Ann Duhart-Green, a new APPA board member, a native Atlantan, born at Grady on Sept. 29, 1948. When I came to know myself, I already had polio. My mother told me I was diagnosed at 2½ years old. I am the oldest of four children. I will have been married to my husband, Henry, for twenty-five years on September 2, 2007.

I attended Bethune Elementary School, Washington High School and Clark College all in Atlanta, and the University of West Georgia where I received a master's degree in Psychology and Organization Management, during my employment at IBM Corp. My plans are to pursue a doctorate in Christian Counseling in the near future.

As a child growing up with polio, I was very adventurous, attempting to do everything my three brothers and the neighbor kids did: ride bicycles, skate, dance, etc. My work at IBM Corp in various positions over twenty years was challenging and extremely demanding; however, it opened up a whole new world of opportunities and experiences to me. I traveled places and met people I never would have been exposed to otherwise.

Reading brings me great joy and pleasure. I love to travel and I meet no strangers. However, mentoring challenged young people is my purpose, encouraging them to develop their inner spirit of greatness, despite the circumstances and conditions they may find themselves in as young people. As a result of having polio, I have been associated with Emory School of Medicine for over fifty years and presently serve on the Community Advisory Board. At some point in the future I plan to establish a foundation to fund my mentoring projects for challenged young people and my contributions to Emory School of Medicine Rehabilitation Department.

As all of you know, this polio business has its challenges and restrictions and they are many. However, polio has been the least of my challenges, as I have chosen to focus on all of the things I can do — take care of my health, live as well as I can, for as long as I can, helping anyone I can along the way!

Motto: It is not how many times you fall that counts but how many times you get UP!

Modafinil Study Conclusion

A study in the May issue of *Neurology* [*Neurology*. 2007 May 15;68(20):1680-6] concluded that “based on the utilized measures of outcome, Modafinil was not superior to placebo in alleviating fatigue or improving quality of life in the studied post-polio syndrome population.”

The abstract can be found at PubMed –www.pubmed.gov.

MARIE'S VOICE

by Marie Latta

Go, Razorbacks! I was thrilled to see in the APPA Spring 2007 newsletter that the University of Arkansas was awarded a research grant for Post Polio study. That's my Alma Mater. My brother Dick and his family live in Siloam Springs, near Fayetteville. Dick also had a mild case of polio in 1949. With what we know now, he was likely one of those whose body was invaded by the virus but never actually took hold. His wife Lydia (who is much younger than my brother) had polio in 1958 at the age of one. It paralyzed her legs and did significant damage to her spine and hands. Lydia's seventy nine year old Aunt Ellen had it then also. And they had a one-year-old cousin who died. Aunt Ellen was one of the early proponents of PPS support groups. She was pushing involvement when Lydia and I thought we didn't need it! I hope they will get involved in the University of Arkansas research study.

Speaking of Arkansas, I just returned from 12 days there. My first trip with my *Twin Tubes* was trouble free, manageable, and fun. My son flew here and drove me to Arkansas. Then my brother drove me home and flew back. I am blessed. First I was with my son and family at the Wharf Resort in Hot Springs. It is a wonderful old resort town where the therapeutic springs have long been a draw. The water actually is very hot coming out of the ground. But I had all the usual access challenges in Hot Springs. I could get into the resort unit but really had to "make do" inside. The only way I was able to manage the bathroom was because I can do a stand pivot transfer. In the historic downtown, there were curb cuts at all the corners. But many shops had steps or thresholds that are about four inches. The big disappointment was that the massages were not accessible. The massages and hot baths are the big tourist draw.

I got to spend a week with my Texas grandbabies. Anna is 2 ½ and AJ is 15 months. Needless to say the time together was priceless. Then I spent four days with Dick and Lydia in Siloam Springs. Six years ago they moved into a totally accessible home they had designed and built. The subdivision is new and all the homes are one level. All of them could have been built with a no step front entrance, but most have a step. My brother talked about how it simply did not cost more to build in access (about a ten dollar difference in doors). My brother has long been a collector of antique furniture. Lydia is second generation Italian American and their home reflects old world beauty. There is nothing about it that says rehab or that awful word "handicapped".

They should get it featured on HGTV or a magazine. Dick was not familiar with the *Visitable Homes* movement. But their home is a model for it. I had the blessing of total access plus the warmth of my family! Their subdivision doesn't have sidewalks, but Lydia and I took daily strolls on their quiet streets where people actually slowed down for us. With a recent sidewalk ordinance, they are hoping to get them in their neighborhood. We all need to say a big thanks to fellow polio survivor Eleanor Smith and keep the flags waving for *Visitable Homes* and community access until it becomes a national standard!

Twin Tube Report! In April I had my trach tube changed by a Shepherd Center Respiratory Therapist, just simple maintenance (like having an oil filter changedJ). The stoma (the hole in my throat) is well healed and I had a healthy winter and spring allergy season. The first week in May I had my feeding tube (remember the unruly child?!) changed because some spots were forming inside the tube and I couldn't get them cleaned out. I have no desire to be a Petri dish. The doctor did not want to change it, saying it was so much cleaner than he sees in other folks. Not to be deterred from ridding myself of any unnecessary bacteria, I pushed my way into getting it changed in the outpatient GI lab. I called the manager of the Piedmont Hospital GI Lab and stated my case. I told her, as I had told the doctor, that I did not want to wait until just before my trip, then risk having problems. Since I have been like a gnat that won't go away, she called my GI doctor and set it up.

This tube has a leaking port just like the last one, so I'm still using the crimping and bread bag twister to keep the fluids and nutrients inside where they belong. In spite of the leaky port, I like this tube. It has a maximum 20 cc balloon, rather than the 3-5 cc of the first one. So now if some of the medical people put 10 cc's in it, they won't rupture the balloon. I am still waiting for them to have an Aha moment about the connection between over-inflation, rupturing balloons, and feeding tubes falling out! I've built a relationship with the manufacturer, who is interested in my experiences with the tube.

Never lose sight of your inner strength. May each of us find a reason to celebrate each new day.

Special Thank You to the Following Members for their Extra Financial Contribution

Ann Coultrip
Ann McWilliams
Virginia Malone, MD
Frankie Lewis

Recent APPA Programs

April

APPA members met at Emory Rehab in April for a panel presentation by members who attended the International Post Polio Conference in Miami. Handouts and additional information are available on our website at www.atlantapostpolio.com Thanks to Bill Crowell for traveling from Waverly Hall to assist with our panel discussion

After the presentation, Linda Priest led the annual business meeting. Sylvia Gray gave the financial report and a discussion followed. Other board members in attendance were Barbara Reynolds, David Jones and Shirley Duhart-Green.

June Social

On Saturday, June 9, 2007, a group of 24 APPA members and friends gathered at Carino's Italian Grill in East Point. It was a time of renewing friendships and forming new bonds with others. Our after lunch entertainment was provided by Vicki Crowell as she presided over many games of bingo. Thanks to David Jones, Thad Lewis and Cheryl Hollis for the prizes.

If we were to give a prize for the greatest distance traveled to attend, it would have to be shared by Herbert and Barbara Ruecksties coming from Oxford, Ga., and Jack and Lynda Dillman coming from Covington, Ga. Both couples traveled about 100 miles round trip to be with us. Way to go! Once again we can say that a good time was had by all.

August

APPA members met for lunch at the Blue Marlin Seafood Restaurant on Pleasant Hill Road in Gwinnett County. David Jones shared his experience meeting with fellow polio survivors in Kenya. Everyone enjoyed seeing David's pictures and listening to him share about his recent missionary trip to Africa.

...New Polio Books...New Polio Books...New Polio Books...New Polio Books…

(Request them from your local library)

Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome by Lauro Halstead, M.D. This is a new, completely revised and updated edition of Dr. Halstead's previous book with an emphasis on aging. The paperback sells for $13.95 and can be ordered by calling LaShonne Williams-Fraley at 202 877 1010.

The Post Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families by Margaret Backman, Ph.D. In this book Dr. Backman examines polio survivors' psychological reactions to their earlier experiences and to their current struggles with the late effects of polio. The book also includes a practical guide for coping with the emotional aspects of PPS. The book sells for $18.95 and can be purchased by calling 1-800-288-4677, Ext. 501. It is also available through Amazon.com and barnesandnoble.com

Elegy for a Disease: A Personal and Cultural History of Polio by Anne Finger. Through the eyes of a polio survivor, this book focuses on the experience of people who had the disease, and explores discrimination; the disability rights movement and casts a critical eye on medical treatment. The book is available at many bookstores and online at http://www.powells.com/partner/31254/biblio/031234757x

Warm Springs: Traces of a Childhood at FDR's Polio Haven by Susan Richards Shreve This is a beautifully written memoir of an era written by a patient at Warm Springs at the height of the polio epidemic. The book sells for $24 and can be purchased through Haughton Mifflin Press.

The Cure by Varley O'Connor. This book is a richly complex portrayal of the lives and times of a family emerging from the Depression only to have their three-year-old son fall prey to polio. Consortium Books, 1-800-283-3572.

Thank you to the March of Dimes for Their Donation to APPA

The mission of the March of Dimes is to improve the health of babies by preventing birth defects, premature birth, and infant mortality. As the leading national health organization dedicated to saving babies' lives, the March of Dimes advances its mission through research, community services, education, and advocacy. The March of Dimes has a 69-year track record of success in saving millions of babies from death and disability and bringing people together to solve complex health challenges.

Many people remember the March of Dimes for conquering the polio epidemic. The March of Dimes continues to support this legacy by funding research and education surrounding polio and post-polio syndrome.

The March of Dimes has contributed to research focused directly on post-polio syndrome and, in our ongoing birth defects research program, invests heavily in investigations of basic biology of the central nervous system, and area of research clearly relevant to post-polio syndrome. In addition, the March of Dimes supports federal funding for research on post-polio syndrome through the National Institute of Health.

The March of Dimes supports funding of education, publications, and conferences focusing on global polio eradications and post-polio syndrome. Up-to-date Public Health Education Information Sheets are maintained on both subjects. In 2001, the March of Dimes published two reports from an international conference that it sponsored along with the Roosevelt Warm Spring Institute for Rehabilitation on post-polio syndrome. The reports, *Post-Polio Syndrome: Best Practices in Diagnosis and Care*, and *Guidelines For People Who Have Had Polio,* were written to inform and empower both providers and patients so that they can work together as a team to develop informed individualized treatment plans. Both reports are accessible through the March of Dimes website at marchofdimes.com.

Historians have called the conquest of polio one of the great achievements of the 20th century. Thanks to the March of Dimes, and the millions of people who supported it, we no longer have to fear another devastating polio epidemic like those that terrorized previous generations.

Although the March of Dimes redirected its mission to improving the health of mothers and babies, it has not forgotten its historic legacy. Our continued support of education and research on global polio eradication and post-polio syndrome help continue to fulfill that legacy.

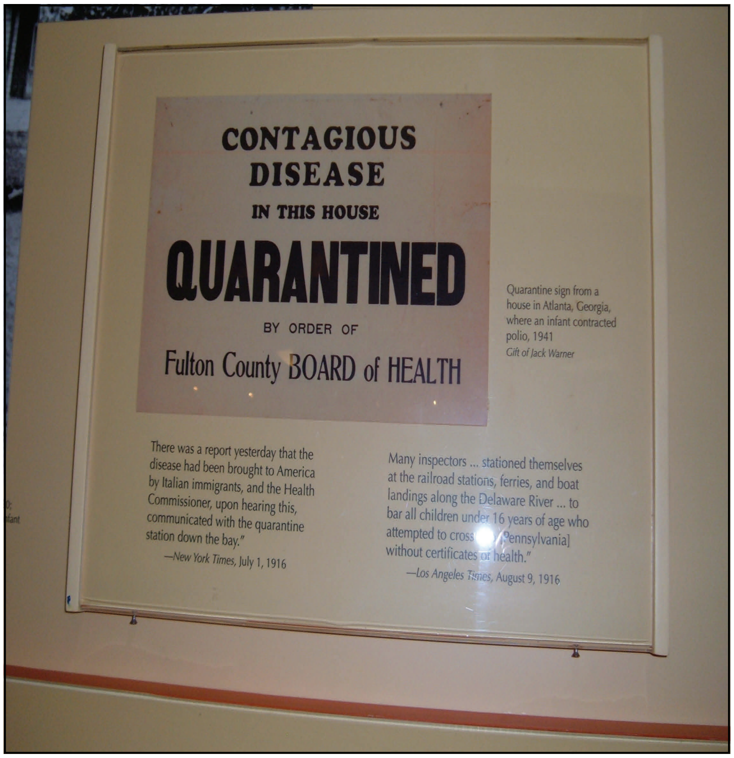
March of Dimes generous donation made this edition of the APPA News possible

APPA ATTENDS THE WARM SPRINGS COLUMNS CAMPAIGN CELEBRATION

APPA Members who attended the Warm Springs Columns Campaign Celebration are seated left to right: Marc Gunter, Dave White, Linda Priest, Roberto Moraes. Standing left to right Sharon Gunter, Suzanne Verret, Barbara Reynolds

The pictures depicting the polio epidemic tell it all...

Pictures are from the Smithsonian Exhibit at the Warm Springs Columns Campaign Celebration.



CONTAGIOUS
DISEASE
IN THIS HOUSE
QUARANTINED
BY ORDER OF
Fulton County BOARD of HEALTH

Quarantine sign from a house in Atlanta, Georgia, where an infant contracted polio, 1941
Gift of Jack Warner

There was a report yesterday that the disease had been brought to America by Italian immigrants, and the Health Commissioner, upon hearing this, communicated with the quarantine station down the bay."
—*New York Times*, July 1, 1916

Many inspectors ... stationed themselves at the railroad stations, ferries, and boat landings along the Delaware River ... to bar all children under 16 years of age who attempted to cross [illegible] [Pennsylvania] without certificates of health."
—*Los Angeles Times*, August 9, 1916

The Following is the Warm Springs Alma Mater which was sung by everyone at the Columns Dedication Ceremony, in Roosevelt Hall on July, 2007

Come and sing a song of
Warm Springs
To a place we love so well
Where good friends and
loyal friends
Have cast a magic spell
On a hilltop green with pine
trees
Stands our Alma Mater dear
Giving all her hope and courage
Through each passing year

There's the walking court in sunshine
There's the laughter in the hall
And the quiet peace of evening
Sheds a romance over all
Hail to thee our Alma Mater
True to you we'll always be
All our memories we will treasure
Of our Warm Springs family.

Entrance to new Smithsonian Exhibit at Warm Springs

Connecting with each other at a Smithsonian exhibit.

Upcoming Event

Note Date Change/Mark Your Calendar

Announcing the Next APPA Meeting

Dr. Leslie to Speak to APPA

10:00 am, Saturday, November 3, 2007
Shepherd Center, 6th Floor

July 2007 APPA Membership Directory

A giant thank you to Sylvia Gray for making our new directories possible. If you are a dues paying member, you should have received your copy in the mail last month. Please let us know if there are additions or corrections. The corrections will be published in our next newsletter.

MEMBERSHIP IN APPA

Return TO: APPA, P. O. Box 250566, Atlanta, GA 30325
Make checks payable to: APPA

Individual ☐ $20 Family ☐ $40 Corporate ☐ $75 Lifetime ☐ $400 Additional Contribution ________

Name (s) ____
Address ____
City State Zip ____
Telephone ____
Email Address ____

Annual contributions help to educate the public and health care community concerning polio. We respond to the needs of individuals who suffer from post-polio syndrome through group meetings, educational programming, newsletters and advocacy. APPA is a 501(c)3 non-profit corporation. All contributions are tax deductible.

Please **CHECK** one.

- ☐ I am a new member. ☐ I am renewing my membership.
- ☐ I've already sent my tax-deductible annual membership contribution, but my contact information has changed as shown above.
- ☐ I am unable to contribute at this time but would like to receive the APPA News.

We need you! Would you be willing to serve APPA in any of the following areas?

- ☐ Membership outreach (phone calls to shut-ins)
- ☐ Public Relations
- ☐ Data base assistance
- ☐ Planning a conference
- ☐ Fundraising
- ☐ APPA phone tree help
- ☐ Assist with social events
- ☐ Newsletter (write articles, proof read)
- ☐ Program planning
- ☐ Assist with answering APPA phone line

Llp/10-2006

Dr. Toby Raper, son of Dr. Pat Raper, was a featured speaker at the recent Warm Springs celebration. Dr. Pat Raper is remembered by many of us who were treated at Warm Springs. Dr Raper served from 1939 to 1973 as head of the Department of Internal Medicine at the Foundation.

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