# \* APPA News \*

The Newsletter of the Atlanta Post-Polio Association

Volume 17 Issue 4

www.atlantapostpolio.org

October—December 2002

#### **Board Members**

President

Linda Priest

First Vice President/Programs

Vacant

Second Vice President/Outreach

Vacant

Secretary

Diane Baggett

Treasurer

Svlvia Grav

Director – Historian

Vicki Crowell

Director-Librarian

Irvin Massey

 ${\it Director-Membership/Database}$ 

Alan Mitchell

Director - Social

Peggy Peay

Director - Web Master

Gus Pettit

Director

Dick Weir

Ken Wencl

Newsletter Editor - Alan Mitchell

APPA News is published quarterly by the Atlanta Post-Polio Association. Please address all correspondence to:

Editor, APPA News P. O. Box 250566 Atlanta, GA 30325

Letters of general interest will be published in future issues as space permits. We reserve the right to edit all letters for reasons of space and clarity. We will withhold your name upon request, but no unsigned letters will be accepted for publication. Opinions expressed in letters do not necessarily reflect the views of the Atlanta Post-Polio Association.

#### **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. Articles reflect the opinions of their authors and do not necessarily reflect the official policy of the Atlanta Post-Polio Association.

Permission is granted to electronically reproduce any article from APPA News for non commercial purposes as long as proper attribution is noted.

Articles for next issue of APPA News are due to the editor by Feb 15, 2003. E-mail:

editor.APPANews@mindspring.com.

## President's Message

"...we have

worked hard..."

s we approach the end of the year, I have become nostalwhile thinking gic about how grateful I am to be a member of APPA and to have such an extraordinary organization of people in the Atlanta area. I am grateful for each one of you. I am grateful to have so many intelligent, energetic and dedicated people serving on our Board of Directors. I feel blessed to have a medical center like Shepherd supporting us and providing so many services free of charge.

Despite the many changes on the board, we have had a good year. In

a depressed economy, we have been able to provide all of our services while staying within a significantly reduced budget. We've worked hard to add additional money to our Special Needs Fund. New books and tapes have been added to our library, and we have added new members to our roster. Our monthly programs have been great including such speakers as Mike Galafianakis who is Georgia's State ADA Coordinator, Dr. Anne Gawne from Warm Springs, and Dr. Paul Peach from Albany. Many of our

members provided interesting programs and Dr. Dean Ericson and Dr. Steve Shindell helped us focus on psychosocial issues and PPS. All of this and a successful conference too!

Dr. Lauro Halstead traveled from NRH in Washington, DC, to present a one-day conference entitled "PPS Into the 21st Century." He had exciting news for us about new research using a post-polio mouse model. This holds much promise for testing new therapies for PPS. The goal is to start clinical trials in human

subjects in the near future. One hundred thirtyeight people from five states

attended our conference and enjoyed not only Dr. Halstead but also a Q & A session that included Shepherd's own Dr. Donald Leslie and a floor full of exhibitors who showed off their latest wares. We made new friends and learned from other support group leaders.

(See a detailed article about our conference elsewhere in this newsletter.)

It has been my honor and privilege to serve APPA as President this year. You are like family to me. I feel a deep bond

(Continued on page 8)

## REPORT ON THE CONFERENCE PPS INTO THE 21ST CENTURY WITH DR. LAURO HALSTEAD

By Diane Baggett

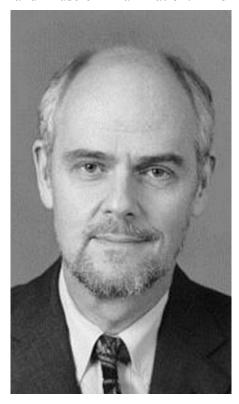
Halstead is director of the post-polio program at the National Rehabilitation Hospital in Washington, D.C. He also is a polio survivor.

Dr. Halstead defines his general health as excellent with the exception of post-polio. In his eagerness to find solutions to symptoms, he has tried every prescription and other remedy that has come along, including herbs and magnets.

His acute onset of polio was in 1954 at age 18, while he was traveling in Europe after his freshman year of college.

In this first stage, he went from an iron lung to no assistive devices and considered himself cured from 1957. In 1982 at 28+ years after the initial onset, the post acute stage began. He experienced decreasing strength over 20 years, measuring the progression by the number of city blocks he was able to walk. In 1983, he bought his first scooter In 1990 he was fitted with an ankle/foot orthotic. In 2000, he got his second scooter and a van with a curbside lift. He also uses a manual chair when he has a pusher.

For symptom management, Dr. Halstead identifies 3 primary symptoms: weakness, fatigue and pain. Weakness is often due to overuse. The fatigue can be both brain and muscle. The pain may be secondary to weakness and muscle inflammation. To



treat fatigue he recommends pacing oneself, scheduling rest periods and taking naps. Weakness may be treated with bracing, pacing devices and wheels. The pain may be alleviated by heat, massage and stretching. Reducing activity and modifying one's lifestyle may reduce pain.

To manage pain in one's daily life, first make the home accessible. Dr. Halstead showed slides of his home and of himself using adaptations. At work, he

schedules a daily nap in a reclining chair, using a blanket, headset with relaxation tape, pillows and a note on the door, "Therapy Session in Progress."

Our generation is the first to have the benefit of rehabilitation. We moved through life at great cost, with a balancing act which aging disrupts. Instead of making peace with disability, one must incorporate it into one's life including changes as they occur.

The afternoon session covered potential new therapies. Growth factors are naturally occurring and promote as well as stabilize growth of nerves and muscles. Stem cells can become any cell type in the body. The hope is to replace damaged cells with new healthy cells. Another area of research is dynamic bracing. The braces are made of a carbon fiber composition. They provide active support and substitute for some muscles.

The most exciting new research is what Dr. Halstead termed the "polio mouse." Mice are given a modified polio virus. This allows researchers to investigate causes, treatments and new therapies.

Attendees were invited to submit questions for Dr. Halstead which he answered with assistance from Dr. Leslie of Shepherd Center and Dr. Anne Gawne of Warm Springs.

## THE POLIO MOUSE: NEW HOPE FOR POST-POLIO SURVIVORS

ost-polio syndrome (PPS) is a disorder that affects polio survivors 25-50 years after their original infection. It results in a wide array of disabling symptoms including new weakness, overwhelming fatigue, muscle and joint pain, muscle atrophy, respiratory difficulties and temperature intolerance. Many patients who experienced substantial recovery from their original illness now find themselves returning to the wheelchairs, braces, and breathing devices they thought they had left behind long ago. There are an estimated 600-700,000 polio survivors in the United States, as many as 20 million worldwide, and up to 60 percent of these individuals are expected to suffer from some degree of disability from PPS. Unfortunately, because polio is virtually an orphan disease in the United States, the large population that received the public's attention and financial support in the 1950s and 1960s has been neglected in terms of research just as these new manifestations of polio have become apparent.

#### The Polio Mouse

In the spring of 2000 at Upstate Medical University in Syracuse, New York, work was begun under the leadership of Burk Jubelt, M.D., on developing a post-polio mouse model for the purpose of testing new therapies for PPS. It is anticipated that the mouse model will be completed in the summer of 2002 and will then be available for wide use by other research scientists to test novel therapies. Private money supplied by polio survivors has, to date, funded the majority of this work. However, additional funding is required to put this research on a "fast track" with the goal of starting trials in human subjects in the next several years.

#### Why the Polio Mouse Offers Exciting New Hope

The polio mouse offers new hope for several reasons: 1) Fast Tracking. This is the first time there has been a small animal model for PPS. Many of the successful treatments and cures for other diseases began with an animal model that had an ill-

ness similar or identical to the human illness. A mouse infected with the polio virus will develop PPS in 6-8 months. This means researchers can try new therapies and know if they work in less than a year rather than waiting for years to get results; 2) Piggybacking. Polio mice can be easily shared with other labs. This makes it possible for established scientists from many disciplines who are investigating related disorders such as ALS to work on PPS simultaneously. With relatively small amounts of money, these researchers can add polio mice to their therapeutic trials alongside the animal models of other diseases already being studied. Researchers who have expressed an interest in PPS trials include neurological and molecular investigators at Johns Hopkins University, Harvard Medical School, the University of Pennsylvania Medical School, the University of California-San Diego and many others, in addition to the team at Upstate Medical University; and 3) Novel therapies. In recent years, medical research has made unprecedented discoveries that appear to have direct application in treating PPS. These include novel therapies such as stem cells in the areas of neural protection, repair, and regeneration. Already, some of these discoveries have been used to treat other neuro-degenerative diseases such as ALS, stroke, and Parkinson's disease. The ultimate goal of the polio mouse research is to slow, stabilize, and possibly even reverse the progression of symptoms of PPS in polio survivors here and around the world.

#### How you can help

Donations can be made directly to: Upstate Medical University Foundation 750 East Adam Street Syracuse, NY 13210

Make checks payable to Upstate Medical University Foundation/Post-Polio Project. Upstate Medical University Foundation is a 501(c)3 corporation. For more information, contact Mr. Robert Morris at 203-353-5901, Lauro Halstead, M.D., at 202-877-1661 or Burk Jubelt, M.D., at 315-464-5357.



Longtime APPA member and polio survivor, Mary Lou Toohey died September 4, 2002, after a long battle with cancer. She was a native of Detroit Michigan but had lived in Atlanta since 1969. Her husband, John, their children, Mary Ann Brandt, John S. Toohey and Richard Toohey, eight grandchildren and one sister, Janet Downs, survive her.

Mary Lou had polio in the early 1950s. She was very health conscious, had an exercise program and practiced healthy nutrition. In addition to being a member of APPA, she was a member of The Atlanta Historical Society and The Needle Point Guild.

Contributions to APPA in her memory have been received in the amount of \$1,125.00. This money will be used to purchase needed equipment for polio survivors.

A Book will be placed in the APPA library in her memory.

#### Donations Honoring the Life of Mary Lou Toohey Atlanta Post Polio Association

Donald and Doris Nelson

Sylvia Gray

Peggy Peay

Bonnie Bonham

Susan Cameron

Milton & Ann Smith

John, Susan & Christian Osberg

Lila Blake Horne

**BACK Associates** 

Michael, Rebecca & Daniel Cohen

Howard, Kelli & Henry Veit

Jane Barron

Frances O'Reilly

Mary Alden

Shirley Reeves

Robert & Shelby Rosser

Beth & Gene Jary

Mary Jane & Jerry

Martha & Donald Grimm

Bob & Patricia Hall

Patricia Sullivan

Margaret Walton

Patty & Don Gifford

Valencia McClinton

Sharon Kavanagh

Ms. Clye Thomas

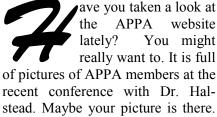
Alan Brandt & Saundra Goodman

Ms. Edward Lide

Jim & Betty Ann Bennett

### APPA ON THE WEB

By Gus Pettit



recent conference with Dr. Halstead. Maybe your picture is there. Maybe you don't want your picture to be there. So take a look. If you are there and really object to being there then please send me an E-mail at gusp@mindspring.com and I will reluctantly remove your picture.

What I'd really like for you to do, however, is take a look at the website and make suggestions for things to add. For example, there is a list of links to all the facilities in Georgia that have "post-polio clinics." Maybe there are others that should be included or just the name of a physician or health care provider you'd like to recommend. We also try to maintain an up-to-date list of upcoming events that are of interest to APPA members. Please let me know if I've missed anything.

Finally, it is time to add another article based on the experiences of an APPA member. Most of you, no doubt, have read the wonderful "Letters from the Polio Years" on the APPA website, which is a collection of letters written by the parents of Marsha Griffin, a long-time APPA member, during the years of her recovery from polio. If you want to tell your story and can mail pictures for me to scan or E-mail pictures that you have on your computer, please send it all to me. Of course. Alan Mitchell would like to have material like this for the newsletter but we can do a better job with pictures and have more space on our website.

## ACCESS ABILITY

By Linda Priest

a recent Status Report from the Department of Justice a long list of interesting lawsuits were settled which opens doors for people with mobility impairments. The following is a sampling of these decisions which you can use as you encounter barriers in your own hometown. This is news that you can use.

A negotiated consent decree against **Burger King** was filed resolving a lawsuit alleging that Burger King failed to remove architectural barriers to access. The decree ordered Burger King to remove barriers at 17 company-owned restaurants in New Hampshire by adding accessible parking spaces and appropriate signage, providing accessible routes to and from the parking lot and throughout the restaurants, and making restrooms accessible to individuals with mobility impairments. Burger King also agreed to pay \$50,000 in civil penalties to the United States and \$5,000 to the complainant.

The Department of Justice reached a settlement agreement with the **City of Warren, Ohio,** over a complaint by an individual with a mobility impairment. The complainant filed the lawsuit because the municipal justice building was not accessible. The city agreed to a wide range of measures to improve accessibility at all of its facilities including accessible routes to jury boxes; directional signs indicating the location of accessible features of buildings; physical modifications to provide accessible parking, entrance routes, doors, restrooms, service counters, and drinking fountains.

SuperShuttle will improve services to travelers who use wheelchairs after a signed settlement agreement which ensures that the nation's largest door-to-door airport shuttle company will provide the "same level of service to wheelchair users as it provides to the general public." The company will have two accessible vehicles at each of its 11 corporate locations nationwide within a year, as well as standing subcontracts with accessible transportation providers to meet overflow demand. Additional accessible vans and subcontracts may be necessary after review of an 18-month survey to determine the

timeliness of pick-ups for the general public as compared to wheelchair users.

Other Settlement Agreements include the following:

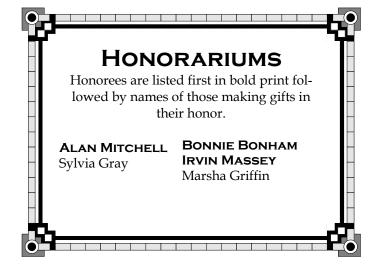
### ► Pleasant Holidays, Westlake Village, California

Refused to guarantee accessible transportation to and from the airport when booking a Hawaiian vacation. They were required to amend their policy on airport transfers and paid the complainant \$6,000 in damages.

#### **▶** Dillard University, New Orleans, Louisiana

Stern Hall, which houses the campus auditorium, was not accessible and had undergone substantial renovation since January 26, 1992, and had not complied with the ADA. Dillard agreed to remove barriers by adding ramps, modifying doorways and adding accessible seating in the auditorium. In addition, they will bring renovations into compliance with ADA Standards, appoint an ADA Coordinator and pay a \$3,000 civil penalty.

These examples indicate how far-reaching settlements become when the Department of Justice is involved. Once the Department of Justice investigates, the scope of the review widens. Offenders of the ADA should beware. The final agreement often includes many more alterations and expenses than the original problem which initiated the lawsuit.



## NEW BOARD MEMBERS

In October, APPA elected three new members to the Board of Directors. Two of the new Board members have provided a brief biography and summary of what they feel is important for the Board in the coming years. Dick Weir's biography is included on page 10.

Thanks to each of you for your vote of confidence that has made me a part of the APPA Board. I hope that I can serve as an advocate for others, to let them know they are not alone, and that by banding together and sharing our experiences and concerns, there are ways of coping with our disabilities.

I had polio at age four in rural Columbus, Ga. I spent nine months at Warm Springs. I began school at age six with leg braces. After several surgeries I was able to function without braces. That worked out very well for many years. Five years ago I began to notice a weakness. "Of course I had an answer to that," maybe I'm working too hard, I'm just getting older, or maybe I just need a vacation!! No such luck. After some research I was told it was postpolio syndrome. Thanks to a nurse in my physical therapy class, I heard about APPA.

The support meetings are very educational and you cannot be with a better group of people. The purpose of APPA is to increase members' knowledge about the late effects of polio and to educate the general public and health care professionals about the care and needs of postpolio persons.

Charlotte Cerry

I was born in New York City in 1940 and was three when I came down with the polio virus. I was in recovery for a year. At first I used a brace and crutches and then was able to walk with a raised shoe. Although my right leg was much shorter and weaker than my left, I was able to enjoy most activities growing up.

I graduated from Columbia University and the University of Virginia Law School. While at Virginia, I met Jim Paulk, whom I married in 1965 and we settled in Atlanta to practice law and raise a family. I was able to cope pretty well with the demands of work and children and could enjoy some outdoor activities like hiking and camping. With the encouragement of my family, I even learned to ski and ice skate at a beginner level so I could share the winter vacations they all loved.

The primary long-term effects of my disability have been pain and fatigue. I've had to give up the more demanding activities but have taken up golf and birding. I plan to start painting and playing the piano when I have to take to a wheelchair. I am prepared to ignore the total absence of talent for these activities.

Carol Paulk

## For the Directory

#### **NEW LIFE MEMBER:**

#### Gloria J. Mims

835 Oglethorpe Ave SW Apt. 601 Atlanta, GA 30310 404.755.7819 gmims@af.publiclib.ga.us

#### **NEW MEMBERS:**

#### Linda Venuto

301 Valley Green Ct Woodstock, GA 30189 770.592.9227

#### Henrietta Sigmon

RR 1 Box 425 Pineview, GA 31071-9731 478.892.2094

#### John Knapp

2895 Castle Dr Lawrenceville, GA 30044 770.381.7875 deknapp@mindspring.com

#### Marsha Cabbage

2088 Trailmark Dr. Decatur, GA 30033

#### **Cindy Sweany**

17 Peachtree Lake Dr. Sharpsburg, GA 30277 770.254.0304

#### **Elmer Jones**

3849 Cotswold Drive Lilburn, GA 30047 770.931.9026 stephanie\_ward@msn.com

#### David Mauldin Bobbi Mauldin

8121 Banks Mill Road Douglasville, GA 30135 770.489.7776 davidmauldin1124@msn.com

## For the Directory APPA MEETINGS

#### **Harriet Adams**

237 Peachtree Way Atlanta, GA 30305

#### Virginia Rosenbusch

4801 Winding Lane Powder Springs, GA 30127 770.222.1689

#### **CHANGES**

#### **Peggy Peay**

5428 Tally Green Dr Marietta, GA 30068-2885 770.587.4019

#### **Shelly Ross**

str4187@aol.com

#### Sally Luck

ZIP change to 29909-5041

#### Susan DeMott

4916 19th St. W. Bradenton, FL 34207 941.755.7205 gatorsam@worldnet.att.net

#### Patricia Dorsett

3180 Peek Road Conyers, GA 30094

#### Barbara Ramsay

4230 River Bottom Drive Norcross, GA 30092 770.368.4070

#### **Betsy Doty**

PO Box 382 Ellijay, GA 30540 706.698.3538 betsydoty@ellijay.com

#### Shelia Reifengerger

300 Johnson Ferry Road NE Atlanta, GA 30328

#### **DECEASED**

Mary Lou Toohey

January 11 Continued discussion of APPA goals and priorities. This discussion is continued from our October Business Meeting.

The discussion will be followed by "Gizmos & Gadgets" presented by Sylvia Gray. Please call Sylvia at 404-471-1180 if you would like to show a gadget that makes your life easier.

February 1 Pat Herndon, Noble Learning Resource Center Librarian, will discuss resources within the Shepherd library and how to access information. Mina Hong, Shepherd's Volunteer Coordinator, will discuss benefits of the APPA third-Wednesday peer support group meetings. Mina is the facilitator of this monthly meeting. (Tentative)

### Preparing for a visit To your Doctor

Try a Tip for Making Appointments with Your PPS Specialist More Efficient By Marie Latta

Donald P. Leslie has been my Post Polio Specialist since 1993. My appointments with him have become really efficient over a period of time. After my husband, Melvin, died in 1999, I had a huge need to reduce the drain of energy devoted to sheer survival. Dr. Leslie was extremely supportive. But having a short window of appointment time to cover a lot of ground was frustrating me. So I decided to streamline appointment time. And it worked.

This is what I did. One or two days before my scheduled appointment, I faxed my list of needs to Dr. Leslie's office so he could see it ahead of time. Now he expects that from me, and we both feel like we get a lot more done in a short time.

Dr. Leslie suggested I share

my efficiency method with my APPA friends. Actually, his words were, "Marie, tell all your friends to do this!"

### The Agenda Method: Fax or Mail Ahead:

I never go to a doctor's appointment just to see what the doctor is going to say or discover. I always have a list of my own questions and concerns. Here's what I now do. You can try it.

- ► Fax or mail ahead your prepared list so that one or two days before the appointment, the doctor has a list of questions and items you want to discuss.
- ► Follow up with a call by midday on the day before your appointment to ensure that it was received and put into the doctor's hands. (Otherwise, it might just get inserted into your

(Continued on page 8)

#### Preparing for Your Doctor's Visit

Try a Tip for Making Appointments with Your PPS Specialist More Efficient By Marie Latta

(Continued from page 7)

chart and not be seen by the doctor until the appointment.)

- ► Take to the appointment a copy of the list for you and an extra for the nursing staff.
- ► At appointment time when nurse/technician asks you, "What are your concerns?" give them a copy and show them everything is listed.
- ▶ The copy also ensures a back up list for the doctor. And you can make any follow up notes right on the sheet with the list.

#### **Benefits:**

- ► Doctor already knows what is on your mind.
- ➤ You don't have to say everything twice, saving your respiratory energy.
- ► Less time is used by nursing support staff, leaving more for the doctor.
- ► Doctor gets to you sooner and has already read list.

#### What to expect:

► Don't expect the support

staff to be thrilled at first with what you have done. This is a break in their routine.

- ► Clarify with the doctor whether or not your information reached him/her ahead of time.
- ► Ask your doctor to thank the staff for working with you.
- ► After you have done it a time or two, you shouldn't have to follow up with a call.
- ► Continuously work at building a relationship with support staff.

#### Closing thought:

This is simply based on experience with my personal PPS doctor. Many of us who belong to APPA and live in Metropolitan Atlanta see Dr. Leslie. The concept also might work with your other doctors. I also make a list before my appointments with my pulmonologist. Having a list in both our hands keeps me on track and I go out feeling that I have benefited from my appointments. And most doctors are happy to save time.

## GTRADE

WELCOME to gTRADE, a Tools For Life project in Georgia funded under the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (Tech Act), as amended. gTRADE is designed to make assistive technology (AT) devices and services more available and accessible to ALL Georgians with disabilities. This equipment exchange collaboration between individuals and families with disabilities and the Tools For Life project encourages members to offer assistive technology devices and information for sale or purchase to others who may benefit from using technology unneeded or discarded by others. qTRADE which functions like a classified advertisement in your local newspaper is discussed in more detail under General Information.

www.gtradeonline.org

## President's Message

(Continued from page 1)

and sense of kinship with each one of you. I look forward to many new opportunities in the year to come.

The first meeting in 2003 will include a continuation of our discussion about future goals and possible changes to our sup-

port group. We want to hear from you about what you like and what you don't like. What kinds of programs you would like to have this coming year and anything else you would like to share. Please come and be a voice in deciding what is right and what needs changing about

APPA.

We have fresh, shining new faces on the board. New officers will be elected in mid-January. Come and unite with us. Help decide priorities and the best way to implement our mission as a loving, caring support group.

Linda Priest

### POST-POLIO SYNDROME

A Guide for Polio Survivors and Their Families

Book Review by Linda Priest

he effects of polio that occur decades after the disease has run its course—weakness, fatigue, pain, intolerance to cold, difficulty with breathing and swallowing—are often more devastating than the original disease. This book on the diagnosis and management of polio-related health problems is an essential resource for polio survivors and their families and health care providers.

tient Center and director of the Spaulding Polio Center. Lauro Halstead is director of the Post-Polio Syndrome Program, National Rehabilitation Hospital, Washington, D.C.

This essential guide for polio survivors, their families, and their health care providers offers expert advice on all aspects of post-polio syndrome. Based on her extensive experience treating post-polio patients, Dr. Julie K.

"Congratulations to Dr. Julie Silver! Those of us who have had polio, even if we are now symptom-free, are glad to see her address the quandry of postpolio syndrome. Dr. Silver's care, persistence, and reaching out to optimize recovery are heartwarming."—Tenely E. Albright, M.D. Surgeon, Harvard Medical School, Whitehead Institute of Biomedical Research and 1956 Olympic Gold Medalist, Women's Figure Skating

Dr. Julie K. Silver, who has both personal and professional experience with post-polio syndrome, begins the book by defining and describing PPS and providing a historical overview of its diagnosis and treatment. Chapters that follow dis-

cuss finding good medical care, dealing with symptoms, maintaining proper nutrition and weight, preventing osteoporosis and falls, and sustaining mobility. Dr. Silver reviews the latest in braces, shoes, assistive devices, and wheelchairs and scooters. She also explores issues involving managing pain, surgery, complementary and alternative medicine, safe and comfortable living environments, insurance and disability, and sex and intimacy.

"There is much still to discover about post-polio syndrome. This book is a beginning to help a lot of people deal with the repercussions of this chronic illness and validate their possible new symptoms. It is a wonderful guide for today's survivors."—Francis Ford Coppola, Filmmaker

living environment.

Julie K. Silver, M.D., is medical director of the Spaulding-Framingham Outpa-

## Now in Paper Back A "Must + Have" &r Your Personal Library

"[This book] belongs to that small select group that is stylish, informative, and a pleasure to read....[Its pages] are crammed with up-to-date information and useful anecdotes all designed to help prevent or mini-

mize further disability and improve the quality of . . . lives."—Lauro Halstead, from the foreword

"A fine and useful book. For the last several years I have been struggling with my own case of post-polio syndrome, and I know of no other book as comprehensive and authoritative on the subject."—Hugh Gallagher, author of *Black Bird Fly Away: Dis*abled in an able Bodied World.

"Invaluable not just to polio survivors and their families, but to all those in the medical and ancillary professions who are in-

#### POST-POLIO SYNDROME

(Continued from page 9)

clined to dismiss polio as an obsolete disease."—Tony Gould, author of A Summer Plague

"The book is superb."—Don O'Connor, Polio Survivors Surviors Support Group of Western New York Newsletter

"There are, unfortunately, millions of people who would benefit from reading this excellent book: I hope that many of them will have the opportunity. . . . It is hard to think of any aspect of post-polio syndrome that this book does not cover in a clear and sometimes even entertaining manner."—Sir Arthur C. Clarke, Times Higher Education Supplement

"Post-Polio Syndrome is a book written for every person who had polio—and their relatives and friends. The book contains nearly everything anyone ever needed or wanted to know about Post-Polio Syndrome." — Phil Thorpe, Westerly, R. I. Sun

"A valuable contribution to the literature and should be a significant benefit to post-polio survivors and indeed should be read by their therapists and carers."—Transactions (Journal of Royal Society of Tropical Medicine and Hygiene)

Note: We have two copies of this book in our APPA Library for your review. To order your personal copy online at \$15.95 plus shipping and handling go to www.yalebooks.com or www.amazon.com. Fax orders to 1.800.406.9145 or phone orders to 1.800.405.1619.

## BOARD MEMBERS

#### The return of Dick Weir

Hello-again—to my fellow polios in APPA. For those of you who do not know this, this is my second term on the Board of Directors. Previously, I was privileged to serve as your President from 1992 through 1995...three or four years as I recall, Here's a snapshot of my life's history and how polio has affected me over the years.

I was born and raised in a small town in Northern Illinois, oldest of three sons. On my sixth birthday, August 25, 1953, I literally fell and could not stand for over a year. Northern Illinois had a huge polio attack that year. I was initially paralyzed from the neck down, but after four months, the paralysis affected me from the waist down. Doctors told me I would never walk again, but we beat that!

I played basketball, baseball, golf, swim team—a little of everything. I received my Bachelor's Degree in Accounting, worked for 18 months, then went back to school at the University of Illinois, and earned my MBA specializing in Marketing. That's also where I met my beautiful wife, Anita, who now also has her MBA, specializing in International Business.

We lived in Chicago, then in New York City (for 6 years), before moving to Atlanta way back in 1970. I have spent my career working in advertising and marketing, including 13 years here owning my own advertising agency, followed by 7 years as VP of Sales/Marketing at Mitchell's Formal Wear based in Atlanta, a position I retired from in late spring of 2001.

Anita and I have one beautiful daughter, Laura, who is 23 and now living in Charlotte, after receiving her BA degree last May from Wake Forest University. She is an Associate Product Manager for a product line for one of Rubbermaid's subsidiaries.

Finally—I have been dealing with Post-Polio for many years now. I have had 15 leg surgeries, and 3 on my wrist (to fix a wrist shattered in a fall.) The last 12 months alone involved 6 surgeries, including a new left knee. I may now need a new right knee as well.

Our most important mission as a group is to act as a true support group for all our members.

Dick Weir

## HISTORIAN

The photo albums are usually on the back table at most of the meetings. Everyone should stop by and take a look at all the fun we have on our outings and parties. It also includes speakers, newspaper clippings of members and things of interest. When you start with Album One, it can bring back a lot of memories and remind you of the wonderful people who are not with us anymore.

Vicki Crowell

March 2002, an article in the Atlanta Journal-Constitution headlined, "World on verge of eradicating polio." According to the article, the Centers for Disease Control and Prevention

stated that, "Though the campaign has entered its final stages, considerable work remains, said Dr. Patrick Zuber of the CDC."

Later on, the article states that, "Because eradication appears within reach, the World Health Organization is beginning to plan what countries should do afterward, Zuber said. That includes identifying all the laboratories where there are samples of the virus, consolidating the stocks and eventually destroying them, a process similar to what was done for smallpox in the 1970s."

SAY WHAT?

ut then in October of this year, the AJC headline read, "Polio eradication impossible, doctors told."

According to this article, "Dr.

D.A. Henderson, who led the global campaign to eradicate smallpox 20 years ago and is now the government's most highly placed bio-terrorism expert, roiled a scientific meeting here by proposing that the laborintensive \$2 billion effort against

polio be rolled back and routine immunization resumed indefinitely.

So what are we to think? Those of us who suffered through the polio epidemics of the '40s and '50s pray that the March article is true, but truthfully, I fear October.

Alan Mitchell

|        | MEMBER  | RSHU             | <b>PS I</b>   | NAP       | PA                     |       |
|--------|---|------------------|---------------|-----------|------------------------|-------|
| TO:    | APPA  | Individual       | Family        | Corporate | Individual<br>Lifetime | Other |
|        | P. O. Box 250566<br>Atlanta, GA 30325   |                  |               |           |                        |       |
|        | ,   | \$20             | \$40          | \$75      | \$400                  |       |
| ame    |   | Telephone Number |               |           |                        |       |
| ldress |   |                  |               |           |                        |       |
|        |   |                  |               |           |                        |       |
| У      | State ZIP Code (9 digits please)  |                  | Email Address |           |                        |       |
|        |   |                  |               |           |                        |       |
|        | Enclosed is my tax deductible annual membership contribution.  I've already contributed for this year, please change my address as shown above.  I cannot contribute at this time, but wish to continue to receive the APPA Newsletter. |                  |               |           |                        |       |

# Very Special Arts

A benefit of APPA membership is the opportunity to attend art and entertainment events for free through Very Special Arts. To learn about current offerings, call 404-221-1270, ext. 36. For a reservation, call Barbara Forest at 404-634-8875 between 9 a.m. and 9 p.m and leave a message including the following information: name; telephone number; event, date and time requested; and number of tickets (each member with a disability may take one guest). Then enjoy this great perk!



### APPA LIBRARY

APPA's Library is housed in the Noble Learning Resource Center on the first floor of the main building at Shepherd Center. Library hours are Mon-Fri. from 9:30 a.m. to 4:00 p.m. and Sat. from 11:00 a.m. to 3:00 p.m. Board member Irvin Massey is APPA's official librarian.

For your convenience, Irvin brings a small selection of books to each Saturday meeting for you to check out.

### Post-Polio Peer Support Group

In hopes of avoiding heavy traffic we have changed the time of our Post-Polio Peer Support Group meeting to 1:00 PM. The one-hour meeting will still be located in Callaway II Conference Room and is facilitated by Mina Hong. The meeting is for polio survivors only and meets the third Wednesday of each month. This is an opportunity for polio survivors to share concerns in an open and safe environment.

NOTE CHANGE OF TIME!

**Moving?** Since the post office will not forward the newsletter, please let us know of your new address (including all nine digits of your ZIP code) so that we can continue to send you the newsletter. Send address changes to APPA at the address shown below.

We're on the web! www.atlantapostpolio.org

1697-056-404

Atlanta Post-Polio Association, Inc. P.O. Box 250566 Atlanta, Georgia 30325

APPA News

NON PROFIT ORG
U.S. Postage
PAID
Atlanta Georgia
Permit No. 2879