# \* APPA News \*

The Newsletter of the Atlanta Post-Polio Association

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October—December 2003

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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.

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Articles for next issue of APPA News are due to the editor by **January 15, 2004**. Please use new email of: isgi@arkol.com

# President's Message

leaves are turning to gold and there is a nip in the air. How quickly 2003 has flown by! I can hardly believe

has flown by! I can hardly believe that summer is gone and winter is fast approaching. APPA has had another great year.

We've enjoyed three fun socials under the direction of Sylvia Gray, and our end of the year Holiday Party is yet to come. We met in the spring at the High Museum of Art to enjoy a wonderful exhibit of French paintings. In lieu of our usual May picnic, we were treated to a bingo breakfast with a delicious spread of edibles and great prizes. Just last week we were treated to a trip to Fernbank Science Museum. In addition to enjoying the museum we went to the IMAX theatre and saw Shackelford's Antarctic Exploration.

Our monthly speakers, also under the direction of Sylvia Gray, have been informative and enlightening. Emory doctors have spoken to us twice this year. In the early spring Dr. Jay Uomoto spoke on disability and spirituality. In the summer Dr. Rao and Dr. Long provided information about the Emory Polio Clinic and the status of polio in India. Dr. Dean Erickson, Shepherd Psychologist, spoke twice. He facilitated a rap session for our general membership and later returned to facilitate our first "Polio Partners" session. We had other great meetings including Bonnie Bonham's presentation on "Easy Living Homes" and Pat Herndon's presentation on Shepherd's Noble Learning Resource Center.

We have updated and printed a new membership directory, and revamped our phone tree notification service. We have started an outreach effort to our spouses and significant others which includes a quarterly meeting for our "Polio Partners." Early this year we took over facilitating our own Peer Support Group Meetings, which have grown and blossomed under Diane Baggett's leadership. We have the option of extending the length of this once-a-month meeting to an hour and a half starting in 2004.

And, the year is not over! Becky Washburn will come in November to tell us all about *Promotion* at Shepherd; and the Holiday Party follows in December.

Our Board has been hard at We've changed around work. some of the duties and now have three board members working on outreach to our membership. We've had our annual business meeting, elected new board members and have some exciting things in store for the coming months. We have added a number of new people to our membership this year. If you are not an active member of APPA you are missing out on good food, good fun and good fellowship. Make it your New Year's Resolution to come and join us.

Linda Priest

# Choughts A Potpourri of Life

By Myrna Whittington

ast year at this time, I missed doing this column, so before it goes any further, Kevin and I want to wish each and all, Happy Holidays, with peace, joy, love and most of all good health!

Thanksgiving and Christmas are going to be small, quiet affairs for us this year, and we are looking forward to them after a very stressful summer and fall. The saying goes that things happen in 3's—how about 6's here at this house!

One night I saw—the one I pine for on Larry King—NEIL DIAMOND!! I immediately dug out all of my albums and boomed the music, even Moby (the bird) loved it, my spirits lifted to the sky along with Jonathan Livingstone Seagull. Speaking of a bird, we have been losing them left and right here with the influx of kittens turned to cats with more kittens. Unfortunately Kev loves kittens so and now they have names. One kitten just loves to sit in front of

Moby's cage and stare, we can see his brain working—aren't you supposed to be outside?????

We lost one kitten after feeding with an eye dropper (my daytime job), now another one has a broken leg, sigh, but impossible to catch for any help. They scamper up along the arbor, and I am forever saving chipmunks (which I love so much). I can see the kittens now thinking, "Here comes the Mad Woman with the broom, again!! Watch out Guys," as they scatter (not really far), then later turn up serenely for their evening house tour.

I just had a "MAD" thought (not unusual for me). Instead of the normal reindeers pulling Santa's sled—how about Roscoe, Fred, Patches, Missy, Braveheart, Sweet Pea, and Jr. —NOW DASH AWAY, DASH AWAY, DASH AWAY, ALL!!

## Very Special Arts Announces New Venues

Four new venues have been added to the list of places offering free tickets for use by Very Special Arts.

Crawford W. Long Museum in Jefferson, Georgia houses memorabilia from Dr. Long's discovery of anesthesia. Visitors can see a recreated 1840's doctor's office, apothecary and a general store.

The Breman interprets the universal themes of tolerance, respect and human dignity through the Jewish experience, with permanent and visiting exhibits.

**Oglethorpe University Museum of Art** on the University campus shows international artwork. This is the *Year of Asia*.

The BellSouth Telephone Museum in downtown Atlanta offers interesting and nostalgic exhibits about the first century of telephone communication.

In addition to calling

404 221 1270 (Ext. 36) to listen to current offerings, you can send an email request to:

jan.truslow@VSAartsGA.org and have the hotline events script sent to you via email. No more having to listen to the recordings over and over to catch dates and times!

(see more about VSA on Page 11 of this issue)

# Impact of PPS on a Polio Partner

Reprinted with permission of the author Dave Van Aken

## Who Am I?

I am not an expert. I am a Polio Partner, not a caregiver. A partner is anyone who works to improve the Survivor's situation. They can be spouses, children, brothers/sisters or friends. I am a Husband and Spouse. Thirty-two years ago, I said,

"I do" for better or for worse, and meant it. I am a Survivor. If necessary, I will adapt every day to our changing situation.

In 1986, Linda was the Office / Purchasing Manager for a paper company in Richmond. She began feeling more and more fatigued and eventually was diagnosed with Epstein-Barr virus (sort of mononucleosis). Following eighteen months of forced bed rest, she returned to the work force, as the Office Manager / Controller of a small printing house. The fatigue came back, and she gradually scaled back her hours. In 1996, she was diagnosed with PPS, retired on disability and went on Social Security Disability.

In the seven years since her diagnosis, we actively participate in the Central Virginia Post Polio Support group. Within the group, Linda is Treasurer (she likes the money), and I lead discussions for the Polio Partners, as well as helping out whenever

and wherever I can.

## Why Are We Here?

When PPS came into our lives, we faced a choice – Fight or Flight. We chose to stay and fight. But what are we fighting for? I am fighting to maintain Linda's Quality of Life, as well as our collective Quality of Life. My guess is we are each here for the same reason.

#### What Is the Impact?

One thing I have found that is true about PPS – each survivor is different. And as each Survivor is different, then each of our situations is different. We do face one common theme: coping with PPS involves a series of compromises. We must remain flexible and tolerant, as we must adjust to our Partner's condition. PPS is progressive over time. The impact or effects could be classed in three stages – Early / Mid / Late.

#### **Financial Impact**

Your family may have a loss in income. You may become the primary income producer for the family. It simply costs more to be disabled. Adaptive devices become necessary or required. Braces, scooters or power chairs. Modifications to your home could include ramps, grab bars, higher toilets. Traveling requires forethought and planning. Public transportation offers more challenges and requires more planning. Personal vehicles may change. You may have to give up your Corvette for a Caravan. Personal vehicles may become minivans to accommodate scooters or electric chairs.

### **Physical Impact**

We have all heard "Conserve to Preserve." This counts double for us as Partners. We try to have our Partners conserve their muscles and adapt to new methods and devices. This is coupled with our own aches and pains as we age and affects our ability to provide care for our Partners.

Sometimes, there is the physical pain we see our Partner enduring. We want to ease this pain, but often can't – bad joints,

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## Impact of PPS on a Polio Partner

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sore muscles, etc.

## **Emotional Impact**

Early on – when we are naïve or unknowledgeable, our expectations can be unrealistic. "If you do all of this, then you'll get better." "When you get better, we'll do this and that."

We (some older Partners in a discussion) scared the "hell" out of a new Partner. As she admitted later, she expected her husband to beat this and they would carry on with the plans they had envisioned for themselves.

Anger, depression and anxiety.

Our Partners thought they beat polio over 30 years ago, and now it has come back to haunt them. Their bodies are giving out, betraying them, and losing functionality. They lose "face" as they succumb to the adaptive devices in an effort to save what is left. Is it any wonder they get angry at the world, and we, sometimes, bear the brunt of it.

## We grieve over our futures.

We – as couples or as individuals – had dreams and desires. While they do not have to be abandoned, they must be reevaluated.

We hurt as we watch our Spouses hurt

At times, they lose their sense

of self. As a culture what we do for a living, or where we volunteer often defines us. As our Spouses curtail this type activity, there is a sense of loss.

<u>Mid-to-late stages</u> - Continual Adjustments have become the norm. We must accept each situational change—and move forward.

Educate Yourrelf – Knowledge Ir Power

These fatigue periods are fairly common. These add more anxiety, anger or depression for our Type A Spouses.

Polio fatigue crashes are real. Linda "crashed" in October of last year. For seven weeks, she was flat on her back. I adjusted. I did the housework, the laundry and the cooking. Before October, my speciality in the kitchen was scrambled eggs or waffles. I provided Linda with hours of entertainment as she directed my efforts in the kitchen. We didn't starve, and weren't poisoned, so I guess we did OK. [Guys – spend some time in the kitchen before you have to. It's a survival skill!]

The hardest part I find in being a Partner is watching the sometimes rapid decline of one

of our Polio friends. We all know it may come. We hope and pray otherwise. We also nag and cajole our Partners into behaving and conserving their abilities.

## Friends and Family

Unfortunately, family and friends often judge our Partners by their appearance. What does fatigue and muscle weakness look like? Part, if not most, of the problem is that they look so normal. There is no disfigurement. Linda did have a slight limp when she was tired or barefooted. The limp is more pronounced now, and she should

always use a cane. Friends can't understand why Linda can't do this or that. They see her in her scooter, using her cane (for without it she is a Weebel).

Friends and family do not understand she must make choices each and every day about the most mundane things. She has a system she calls "energy presents." Every activity uses some energy presents. She has about 10 presents each day. So she

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## Impact of PPS on a Polio Partner

(Continued from page 4)

monitors what she does, and tries not to exceed her 10 presents/day. But, sometimes she does, and she must take extra rest. And if she really blows it out, both of us may suffer the consequences.

Early on, some family members denied anything had changed. One of my sons had the hardest time accepting his Mother (alias "Super Mom") was physically failing. He didn't want to even hear about PPS and we avoided the topic and each other for the first few years. Thankfully, with time, patience and understanding, we now talk openly about what is going on within our lives. But this does not necessarily include extended family. At a some point in time, you have to wonder if the effort is worth the benefit.

### What Can We Do?

## <u>Communicate</u>, communicate, and communicate!

You and your Partner must communicate on your fears, your concerns, and your plans on how to move forward. Sometimes these discussions can become heated – I prefer to think of them as passionate discussions. The more emotional and honest, the better the understanding between both of you.

## <u>Educate yourself –</u> Knowledge is Power

Find out as much as you can about Polio and PPS. Apply

what you learn to your situation. Educate your family and friends. You need the help, and your Partner needs the support.

If your family and friends don't get it, you have a choice – either continue to educate or drop off (another loss). It's your energy you are using, thus your choice.

### Take Care of Yourself

In some cases I know, the Survivor won't let the Partner do certain things because of the fear of getting hurt.

## **Ten Caregivers Tips**

- 1. Choose to take charge of your life, and do not let your loved one's illness or disability always take center stage.
- 2. Remember to be good to yourself. Love, honor and value yourself. You are doing a very hard job and you deserve some quality time, just for yourself.
- 3. Watch out for signs of depression, and do not delay in getting professional help when you need it.
- 4. When people offer to help, accept the offer and suggest specific things they can do. Remember, it may not get done the way you want it to, or how you would do it, but it did get done.
- 5. Educate yourself about your loved one's condition. Information is empowering.
  - 6. There is a difference be-

tween caring and doing. Be open to technologies and ideas that promote your loved one's independence.

- 7. Trust your instincts. Most of the time they'll lead you in the right direction.
- 8. Grieve for your losses, and then allow yourself to dream new dreams.
- 9. Stand up for your rights as a caregiver and citizen.
- 10. Seek support from other caregivers. There is great strength in knowing you are not alone.

## <u>Join Your Support Group or</u> Form Your Own

Many of us belong to a PPS support group. Grab some of the other Partners and go get some coffee while the PPSers meet. Encourage your support group to give you an opportunity to meet separately. Often a general discussion is all the agenda needed.

Central VA PPS group discovered this at our annual retreat about four years ago. We had a Caregivers forum where we openly discussed our concerns, fear, and things that worked. I have been facilitating meetings for Partners about three times each year. We decided last fall to change our "name" from Caregivers to Partners.

There are some online support groups, but mostly they deal with PPS. And for the most part, we Partners don't have a lot of free time anyway.

## NBC'S "AMERICAN DREAMS" DRAMATIZES POLIO SURVIVORS' NIGHTMARE.

Reprinted with permission of Dr. Richard Bruno

ENGLEWOOD, NJ. SEPTEMBER 10, 2003

n September 28, 2003, NBC's award-winning series "American Dreams" (8 p.m. ET Sunday) will begin a year-long dramatization of the pain of having polio as a child and a polio survivor's battle to become "normal" at any price.

"'American Dreams' tells the story of the turbulent 1960s, their pain and promise, through the Pryor family," said Jonathan Prince, creator and executive producer of "American Dreams." "The Pryors' younger son, nineyear-old Will, was not vaccinated against polio because Will's father feared that the vaccine would give him polio." Will contracted polio in the 1959 epidemic, as did 6,000 other Americans, became paralyzed, and afterward wore a long leg brace.

"Having a polio survivor as a character on a hit television series presented a unique opportunity to tell the story of what having polio as a child was really like," said Dr. Richard L. Bruno, Chairperson of the International Post-Polio Task Force. In early 2003 Bruno, who is also Director of The Post-Polio Institute and International Center for Post-Polio Education and Research at New Jersey's Englewood Hospital and Medical Center, called NBC president Jeff

Zucker. "I asked two things," said Bruno. "Would 'American Dreams' be interested in a story about Will having surgery to 'cure' his polio by getting rid of his brace, and would NBC produce and air a public service announcement about Post-Polio Sequelae."

Post-Polio Sequelae (PPS) are the unexpected and often disabling symptoms—over-whelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold intolerance, and difficulty swallowing and breathing—that occur in 75% of paralytic and 40% of non-paralytic polio survivors about 35 years after the polio virus attack.

Bruno received an e-mail from Prince asking him to help write the story of Will's surgery and rehabilitation based on Bruno's 2002 book about polio and PPS, The Polio Paradox. Prince agreed with Bruno that they had an opportunity that was not to be missed. "The pain of America's polio epidemics was already being forgotten by the 1960s," said Prince. "But polio was anything but forgotten by the families affected, like the Pryors, who daily felt its pain. We believe it is important to tell the story of America's polio survivors through that of our nine-

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# Directory 5

## **Prailable**

udos go to Mike
Foss and Gus Petitt
for putting together
the new membership
directories.

If you are a dues paying member, you should have yours by now. Please contact Mike at fossr@bellsouth.net if there are additions or corrections. To date we are aware of the following changes and corrections:

### **Barbara Forest**

barbaraforest@hotmail.com

#### Sylvia Gray

sylviagray@comcast.net

### Sally Luck

37 Fenwick Drive Sun City Blufton, SC 29910-5005 843-705-3234 seluck@hargray.com

Chere are four servings in a pint of ice cream. Each 1/2 cup serving will set you back at least 250 calories.

On other words, a pint of ice cream is worth at least 1000 calories.

## EETINGS appa I

ecause of scheduling difficulty we must change the day and time of two of our meetings in 2004. APPA meetings for the months of February and March 2004 will be on the second Saturday of the month at 1 o'clock in the afternoon. Yes, we are really going to finally have a meeting in the afternoon! Actually, not one monthly meeting but two! Some of us have wanted to try this for a long time and now we are being forced to do it. Please spread the word. Let us hope that all of our APPA members who find it difficult to get up early on Saturday morning will join us for the new time slot. All other meetings for 2004 will be at the regular time (10:00 a.m. to noon) and on first Saturdays except for those with a holiday at the beginning of the month. Our schedule for 2004 will be as follows:

January 10 10:00 a.m. to noon February 14 1:00 - 3:00 p.m. March 13 1:00 - 3:00 p.m. April 3 10:00 a.m. to noon May 1 10:00 a.m. to noon June 5 10:00 a.m. to noon July 10 10:00 a.m. to noon August 7 10:00 a.m. to noon September 11 10:00 a.m. to noon October 2 10:00 a.m. to noon November 6 10:00 a.m. to noon December 4 10:00 a.m. to noon.

### JANUARY 10—NIA TECHNIQUE INSTRUCTOR

Sandy Bramlett, M.Ed., is a Black Belt Nia Teacher and owner of Bodywise Studio in Atlanta. She has studied four intensive levels of training with Debbie Rosas and Carlos Rosas, creators of the innovative Nia Technique. Sandy is also a senior Callanetics teacher, and has taught "functional fitness" and mind/body movement for over 13 years.

The Nia Technique is a gentle yet effective movement for all ages and physical abilities. It's based on the "pleasure principle," the idea that movement should feel good, and stimulate the body, mind and spirit to move to a place of joy.

## FEBRUARY 14—NEW TIME 1:00 p.m.

Annual Business Meeting- Reports for the year ended December 31, 2003 will be given, including the Certified Public Accountant Financial Statements. This is your opportunity to address the Board. Come and be part of the planning for next year. We value your opinion.

We will be planning something special for you to celebrate Valentine's Day. Watch your e-mail for further announcements.

#### MARCH 13—NEW TIME 1:00 p.m.

Travel talk. We will hear from several of our members about the Joys and Problems of Traveling.



Saturday December 6, 2003 From 2:00 to 5:00 p.m.

At Maggiano's Little Italy Restaurant 3368 Peachtree Road NE 404-816-9650

#### 2:00 p.m. Social Hour with Hors d'oeuvres

#### 3:00 p.m. Family Style Dining

2 Salads: Caesar & Spinach

💦 2 Pastas: Meat Lasagna & Angel Hair Pomodor

2 Entrees: Chicken Parmesan & Salmon with

Lemon & Herbs

Lemon & Herbs

2 Deserts: Chocolate Zoccotto Cake & N Y Style Cheesecake

Music by Nancy and Jim Truluck

Door Prizes and Games

Reservations must be in Sylvia Gray's hands by December 1, 2003.

For further information call Sylvia Gray at 404-471-1180

# NBC'S "AMERICAN DREAMS" DRAMATIZES POLIO SURVIVORS' NIGHTMARE.

...parents wanted

to get rid of any

evidence of polio

and to make

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'normal'

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year-old Will Pryor and his parents' desire for him to get rid of his brace, even though it will mean complicated surgery and painful physical therapy."

Childhood polio survivors' having complicated surgery and painful physical therapy were a continuation of the nightmare that was polio. "The original experience of polio and its paralyzing aftermath were terrible by themselves," Bruno said. "But polio survivors experienced even

more horrors." In Bruno's 1995 International Survey, polio survivors reported 34% more physical abuse and 94% more emotional abuse than those who did not have polio. "All of that 'extra'

abuse was the result of looking physically disabled and people's fear of 'catching' polio," said Bruno. "So parents wanted to get rid of any evidence of polio—like the Pryors wanting to remove Will's brace—and to make children appear 'normal.'" Twenty percent of polio survivors in the Survey had orthopedic surgeries and were hospitalized for an average of six months. "Some survivors had not one but as many as a dozen separate surgeries over the years to 'normalize' their bodies," said Bruno. "Young polio survivors were typically not told that they

were having surgery until the morning of the operation, and sometimes not even then."

Surgeries, hospitalizations, and exhausting physical therapy were abusive enough. "Unfortunately, those who were hospitalized were nearly 40% more likely to be emotionally, physically and even sexually abused than were other polio survivors because they were isolated, physically more disabled and therefore slow-moving and easy targets," Bruno said. "Abuse

was polio survivors' ultimate nightmare."

In addition to telling the story of one polio survivor's childhood, Prince has also offered to inform adult polio survivors about PPS. He has agreed

to film a PPS public service announcement with the show's cast that will air during episodes of "American Dreams" and will be aired by NBC during other programs.

Said Bruno, "We are grateful to Jonathan Prince, 'American Dreams,' Jeff Zucker and NBC for telling the story of and educating nearly two million forgotten North Americans, the survivors of polio, their families and health care providers."

For more information about polio and Post-Polio Sequelae go to http://www.postpolioinfo.com/postpolio

## Of Corset Kelps

By Eleanor Smith

Now that the bad pun is out of the way, I will tell my corset story. It even has a happy ending.

Polio at age 3 in 1946 left me a complete quadriplegic at first, but after a few months I slowly regained full use of both arms. In fact, by the time I was a young adult I could out-armwrestle most other folks. I remained a wheelchair user with completely paralyzed legs and a very weak trunk.

At an early age I was put in a cloth corset so I could sit up, replaced at age 8 with a heavy leather back brace and a head piece/chin-strap that immobilized my head. At age 13, when my major growth was over, surgeons fused my spine from nape of neck to waist. Emerging 11 months later from my plaster cocon, I found that not only had I grown breasts, but I could sit up straight with no brace. This was wonderful!

The fusion stood me in good stead for many decades, and still has not disintegrated. Even so, I began to slump badly and in recent years developed very severe back pain. In fact, major back pain has been a force dictating an unfortunate portion of my daily routine and has drained a

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## Of Corset Kelps

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lot of my energy. I went from place to place seeking fixes—at least five visits to Shepherd seating clinic over three years, many visits to the Atlanta Back Clinic, repeated appointments with three different orthopedists, two MRIs, pain pills, a tilting wheelchair obtained from the wonderful Friends of Disabled Adults... plus many homemade attempts to sit more comfortably: straps, pillows, adjustments, stuffed-in pieces of foam, etc.

My several inquiries about bracing to professionals along the way met with responses that discouraged that option. And an APPA member told me about her friend who got a custommade, very expensive, molded, rigid brace and hated it, had to abandon it almost immediately. But I kept wondering...cloth corset? Shepherd had no companies to recommend for cloth corsets, only for custom-formed, rigid braces. Finally I made my own decision to give cloth a try and begged my doubtful orthopedist to write me a prescription.

I went to Hanger Company, just down the street from Piedmont Hospital. Types of corsets were discussed and measurements taken. Five days later I went back to pick up my corset, a cloth affair with stays and three adjustable straps on each side. My back felt better from the moment I put in on. Cost? A small amount for the appointment and just a little over \$100 for the corset, with Medicare paying 80 percent.

But I was cautious. Probably most of us have experienced that small adjustments and adaptations can feel fine at first and then cause their own new problems. In fact, my new posture threw extra weight on a hip with pins left in from a teenage bone break, which is vulnerable to painful bursitis if not carefully protected. But with practice I was able to position myself to protect my hip.

Also I was sad the first morning I had to put the corset on. I cried some—after 47 years brace-free—back to the old childhood memory and Mom's not being there to take care of it any more. One more thing for me to look after, put on, wash, replace. You know the feeling? But even at the time, I knew the sadness would be a one-time deal and routine would set in.

Now it's been three weeks of corset-wearing, and I can say: "It's great!" My back pain is almost gone most of the day. I have taken only one pill instead of one or more nearly every day. One day I went without the corset as an experiment and to rest a place on my rib it was somewhat pressing. My back had healed some, now that it no longer was slumping into the same bad position day after day! Less pain even without the brace! As I type this, I'm wearing the corset, sitting an inch taller than I was a month ago, and feeling virtually no pain. Once again the point is proved, "Sometimes you gotta be your own doctor."

## New Post Polio Book Now Available

By Linda Priest

## Post Polio Syndrome

by Julie K. Silver, MD, and Anne C. Gawne, MD, is now available through Elsevier Press at 800-545-2522. It retails for \$29.95 and is also available from online booksellers and through a link at www.polioclinic.org.

Dr. Gawne died suddenly during the publication of this book and it is dedicated to her by Dr. Silver who writes "To Dr. Anne Gawne, who cared deeply about the health and well-being of polio survivors."

This book is a compilation of materials from many of the most knowledgeable clinicians and scientists in the field of postpolio syndrome. Quoting from the Acknowledgement, "These contributors are heroes to many polio survivors—and for good reason. They are compassionate, intelligent and extremely knowledgeable. They understand the research and know how to translate it into a clinical approach that makes sense. I am deeply grateful to all of them."

Dr Silver is speaking of such highly skilled contributors as Dr. Lauro Halstead, Dr. Daria Trojan, Dr. Neil Cashman, Dr. Frederick Maynard, Dr. John Bach and Dr. James Agre to name just a few. This book will soon be in our library for your review.



National Organization on Disability (NOD) is selling an FDR pin, which is a replica of the inspiring statue at the entrance to the FDR Memorial in Washington, D.C. NOD officials say that the statue of FDR in his wheelchair sends a powerful message that having a disability need not limit a person's potential. It also represents NOD's pride in having led the successful six-year campaign to add the statue to the FDR Memorial, raising \$1.65 million in private funds to complete the nation's tribute to Roosevelt. Of course, to those of us who had polio, the pin represents so much more. We are negotiating with NOD to buy in bulk to reduce the price to our membership. If you cannot wait, you can order the pin for \$14.95, plus \$6.00 shipping and handling for 1-4 pins at National Organization on Disability, 910 16<sup>th</sup> Street, NW, Suite 600, Washington, DC 20006. The pin is 1<sup>1</sup>/<sub>4</sub> x <sup>3</sup>/<sub>4</sub> inch, die struck, bronze-finished lapel pin with deluxe flat-knob clasp.

Please let us know at lindaleepriest@earthlink.net if you are interested in purchasing a pin so that we will have some idea how many to order.

## A VERY FOND FAREWELL

After many years as editor of the APPA News, I'm hanging up my font tables, putting away my text boxes, and sending the graphics and word art to the cleaners for this final issue of the APPA News (at least the "final" on which my name appears on the masthead as editor). It's been fun, and I hope that the articles and information we've brought you over the past nearly two decades has helped you in some small way and has given you a sense of "belonging" to this incredible group of people we call "Polio Survivors."

I would be remiss if I didn't take a few moments to acknowledge the excellent help, assistance and encouragement of Alice Felton who has been my faithful proofreader for several years. Without her sharp eye for detail and inconsistencies, the issues would have arrived in your mailbox with all sorts of problems.

I know that many of you cannot attend our monthly meetings because of distance, energy, disability, or whatever the reason and we've tried very, very hard to provide you with more than simply a repeat of articles that have already been published elsewhere (although you will find two excellent reprints in this particular issue). By the time this newsletter reaches your mailbox, D. R. McKeown has stepped forward and volunteered to continue the tradition of the APPA News.

Alan Mitchell

## Very Special Arts



benefit of APPA membership is the opportunity to attend community events (arts, museums, theatre, sports, festivals, concerts and more) *at no cost* through VSA Arts of Georgia.

To learn about current offerings, call 404-221-1270 ext. 219, or to have weekly e-mails sent to you of upcoming events just send your e-mail address to Jan Truslow: jan.truslow@vsaartsga.org.

For ticket requests call Barbara Forest at 404-634-8875 between 9 a.m. and 8 p.m. and leave a message including the following information: name; telephone number; event; venue; date and time requested; number of tickets and number of wheelchair seatings.

You may also e-mail Barbara with this information barbaraforest@hotmail.com. Then enjoy this great perk.

# Peer Support Group Meetings

We

are having a great time in our Peer Support

Group Meetings. Our group continues to grow. Add it to your calendar for 1:00 p.m. in the Callaway Room every third Wednesday of the month. Diane Baggett is our new leader. Come share and care with other PPSers.

	MEMBER	RSHII	PSI	NAP	PA	
TO:	APPA	Individual	Family	Corporate	Individual Lifetime	Other
	P. O. Box 250566 Atlanta, GA 30325					
		\$20	\$40	\$75	\$400	
Name			Telephone Number			
Address						
City	State ZIP Code (9 digits please)		E-mail 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.



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.



tors in its years of existence, some of

**APPA** Newsletter has had several ediexistence, some of

whom have also been officers or board members of the organization. The 2004 incoming editor of the newsletter has been a member for a relatively short time, but has been an editor and writer in other areas. D. R. McKeown is a former university professor and researcher with advanced degrees in informatics

languages, and liberal arts. He is involved with the State Advocacy Network, FODAC, and a summer camp for disabled children.

A polio since the 1940's, he has been an outpatient at Warm Springs and Emory University Hospitals. Further biographical details will surface in editorials and columns. His hope is to maintain the quality evidenced in the publication through the efforts of predecessors and he encourages input from throughout the organization.

D. R. Mc Keown

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.

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