

APPA NEWS

The Atlanta Post-Polio Association

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FATIGUE

Excerpt from the
Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors®

Fatigue

Unaccustomed or disabling fatigue is one of the most common symptoms expressed by polio survivors and occurs for multiple reasons. Some polio survivors describe fatigue as a decrease in stamina, in endurance, and in the ability to perform repetitive actions (rapid muscle fatiguability), either measured in ambulatory distance or in the performance of upper extremity tasks. Others report a more global sense of tiredness, describing sleepiness, decreased attentiveness, and forgetfulness. Many require more than normally expected amounts of sleep, and frequently feel refreshed by a nap. Many polio survivors also describe a major decrease in stamina following illness, surgery, or trauma (Yarnell, 1988).

While electrodiagnostic studies have shown that polio-involved muscles commonly show signs of chronic denervation/reinnervation and defective neuromuscular junction transmission (**see Pathology**), not all polio survivors experience fatigue. Strength and endurance testing studies indicate that survivors who report new symptoms indeed do have greater residual weakness, reduced work capacity, and recover strength after activity less readily than asymptomatic polio survivors (Agre & Rodriguez, 1990). Gait analysis of survivors indicates that weakened muscles are required to work longer and with greater intensity to compensate for paralyzed muscles elsewhere in the lower extremities (Perry et al., 1987). It is clear that fatigue may result from poor pacing or pushing past the point of "tiredness" (**see Pacing**).

Continued on page 9

Table of Contents:

President's Message 3



5

Thoughts 8

IRS Visits 10

Di\$count\$ 12

Bingo Party 13

Tech Bits & Bytes 17

2011-12 Event Schedule 19

Web hyperlinks are

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Message From The President

Happy to say I've taken a little time off recently. A trip with a dear friend to Tybee Island, Georgia and a rain delayed weekend at the NASCAR race in Hampton, Georgia. I guess this APPA thing is kinda growing on me. I found myself checking out "wheeled" accessibility wherever I happened to be. It started on Tybee when we noticed a guy in a power chair at a sidewalk café where we were having lunch. It occurred to me that there was complete access from the hotel, out the front door, along the street, and up on the sidewalk to the café. Walking along the beach I saw places where the city has placed rubberized mat extending from the sidewalk out onto the beach all the way to the hard sand at the waters edge. It occurred to me that you could then roll on the sand along the beach almost all the way to Savannah, Georgia! Might need to read a tide chart so you can get back home before high tide though;-) It's pretty cool when you can roll from a hotel room all the way down the beach out onto the pavilion to go fishing. Speaking of Savannah, we were exploring a real neat area on River Street with old pre Civil War buildings and cobblestone streets. Some of the buildings were originally used to store cotton so the doors were extra wide. The city has made it accessible too by "bricking" the crosswalks at the curb cuts. Cobblestones were hard enough on my Mustang never mind a power chair. Following that was a camping trip at the NASCAR race in Hampton, GA. I recall years ago attending a race there seated next to a guy on crutches. We got to talkin, yeah I know, big surprise, and he allowed how even though we were sitting in turn four the handicapped parking was over in turn two about a mile away! A long way on crutches. This time I was pleasantly surprised to see a lot of handicapped camping areas and parking close to the stands. It is possible to roll from a camper into the track and right up to the handicapped section. The handicapped seating provided better viewing than many of the general admission seats. I guess the only problem would be access to the camper. I do recall looking at a camper a couple of years ago that had a retractable ramp at the back for

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wheelchair access. It had wide aisles and an accessible bathroom too. I don't know if other sports venues are as accommodating as auto sport. It may be because some of its heroes have spent time in wheelchairs either temporarily or permanently. I was happy to see access alive and well and continuing to improve wherever I went. Don't forget the sunscreen and your copy of **APPA NEWS**! Gotta have something to do while waitin' for the fish to bite or during NASCAR rain delays!

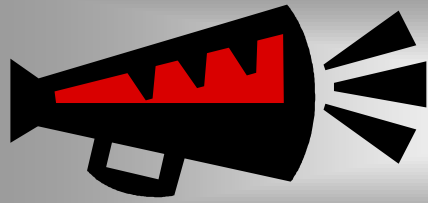
Joe Drogan - APPA President

From the Editor

Isn't it funny how life progresses. Who would've thought I'd ever been editing an article on drug shortages, or any article for that matter. Used to be, a drug shortage was when you couldn't find a bag of weed during spring break. Nowadays it's serious. When pharmaceuticals you need to stay alive are in short supply it's a crisis. When people I'm very fond of are being threatened it's personal. As I was working on the fine article Marie Latta put together for us I did some research too. Both my primary care physician and pharmacist say its economic and political pressures causing the problem. How bad is it going to get? Are we going to be "scoring" blood pressure meds off a dude on Stewart Ave. in Atlanta? There are some ugly things going on. Ask around, do some research and see what you find.

I tried something a little different with Myrna Whittington's "Thoughts" article in using a script type of font. It kinda gives a handwritten feel to it. Tech Bits & Bytes gives a little insight to some of the hardware used to create this publication. Everything including scrap paper, a smartphone, voice recorder, e-mails, tiny and huge computers all come into play. It still amazes me how all of this comes together to create this publication. We've got a very informative article about the IRS and disabilities by Cheryl Hollis. Fatigue seems to be a troubling and little understood issue among us. I found a great article from the fine folks at Polio Health International. And lastly, for you picture fans there's a collection of them from the Bingo Party in here.

Joe Drogan



MARIE'S VOICE

By Marie B. Latta

Drug Shortage

A drug shortage? What!? You've got to be kidding! Where did this come from? Even though the current drug shortage has been going on for over a year, I did not know about it until I read on a forum for feeding tube and TPN (total nutrition through IV) users that some patients could not get all the essential nutrients for their IV formulation. How could that be? Essential to life drugs and formulations just not available any more!?

Then it hit home! On August 22, I did not receive my weekly chemo treatment. My oncology nurse called, late the Friday afternoon before, to tell me my drug was not available. I pulled out my white hat and began researching to try to figure out what was actually going on with hopes of identifying what can be done. My biggest discovery was that it is a convoluted mess. As I talked to my oncology nurse, she and my doctor saw my interest. Dr. Lesesne, my oncologist, went the extra mile and went out and found the two doses I needed to finish my treatment. Dr. Lesesne had felt that I would be OK if he couldn't get it since I was almost finished. That was not the case with another patient. When her drug was not available, they used an alternative drug. She had a reaction and ended up in the emergency room.

It's all about the money. Pharmaceutical companies are not manufacturing the less profitable drugs. This is happening with a wide spectrum of medications, including some antibiotics. Drug companies are blaming the government regulations for being expensive to implement. I have discovered that many drugs are manufactured by multiple companies, some in several foreign countries. That leads me to wonder about quality control.

We all need to keep up with this, spread the word, and write to manufacturers. The FDA web site lists drugs for which there is a shortage www.fda.gov. How can we take action to prevent life threatening drug shortages?

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Things we can do:

- Find and follow the resources for valid and useful updates and information.
- Contact Congress people regarding Senate and HR bills S276 and HR 2245 which, basically, would require manufacturers to give advance warning of shortages.
- Contact FDA and tell your story.
- Contact suppliers and manufacturers to express concern and tell personal stories of damaging effect of not having meds and nutrition.
- Contact local media outlets and ask them to report drug shortages and investigate the causes.

My guess is that a combination of corporate greed and government practices make it difficult for companies to make their profit and want to manufacture the drugs.

- Where is the ethical standard in denying life saving drugs to people who need them?
- It seems that the entire process is so convoluted that it is very difficult for individuals to fight for their right to access to adequate medical and pharmaceutical treatment. But fight we must.
- I want to see pharmaceuticals and any other players in the problem look for solutions instead of just bailing out.
- We need to keep telling our stories to FDA, pharmaceuticals, Congress people, suppliers, and the general public.
- And I will keep looking for names of manufacturers and their contact information.

Action so far:

S276 and HR 2245 have been introduced. Congress was so slow in acting that President Obama signed an executive order on October 31, 2011 directing the FDA to take steps to reduce the shortage.

Sites to follow for information:

<http://www.nutritioncare.org/>

From ASHP (American Society of Health System Pharmacists). They are tracking drug shortages.

<http://www.ashp.org/drugshortages/current/>

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<http://www.tradeindia.com/manufacturers/indianmanufacturers/html>

The FDA:

<http://www.fda.gov/Safety/MedWatch/default.htm>

<http://www.fda.gov/Drugs/DrugSafety/DrugShortages/default.html>

<http://www.fda.gov/downloads/Drugs/DrugSafety/DrugShortages/UCM259864.pdf>

Drug shortage list:

<http://www.fda.gov/drugs/drugsafety/drugshortages/ucm050792.htm>

From Oley Foundation: See www.oley.org.

A.S.P.E.N. Web site (www.nutritioncare.org). Information on bills before the Senate and House committees is at [http://www.nutritioncare.org/News/Industry and Product News/Drug Shortage Crisis Contact Your Legislators/](http://www.nutritioncare.org/News/Industry_and_Product_News/Drug_Shortage_Crisis_Contact_Your_Legislators/)

For information on how to report a shortage to the FDA, go to

<http://www.fda.gov/Drugs/DrugSafety/DrugShortages/default.htm>

or call (888) INFOFDA or (888) 463-6332, or (301) 796-3400.

One thing that reportedly has led to many shortages is FDA inspections of drug manufacturing plants. The FDA has high standards for good manufacturing and sometimes it is expensive to retool plants to meet them for low-cost generic drugs. And while that is happening, the drug isn't being produced. Is this a convenient excuse?

The October 31, 2011 executive order may lead to some changes that can address some of this problem. But it is a tough one. We want drugs to be manufactured in the highest quality possible, and we want to FDA protecting us from shoddy medicines. This costs money, both for the manufacturers and for good FDA inspection, but money that is more than worth it.

What we know is that there is a serious life threatening problem. We cannot afford to sit back and let someone else figure it out. Our very lives could become at risk.

By Marie B. Latta,
November 2011

Thoughts

by Myrna K. Whittington

A Potpourri of Life

What a summer, heat that I thought would do me in! Hurricane landing by the Outerbanks of North Carolina, just where my children are living. I begged them to leave, did they? No-o-o, of course not! Then flooding in my home state of New Jersey, the likes of which I've never seen in my lifetime. More worry about my daughter and grandson up there.

Then, throw in the economy and when I go to pay bills, I really freak out! All I do know is that all of the above, worrying, and freaking out are really bad for the waistline! Even trying to read a good book was not comforting enough, until I found Ranch Doritos and Blue Bell ice cream! That worked!

But now I am kicking myself, why oh why didn't I turn to meditation instead?

Myrna Whittington

Continued from page I

Chronic musculoskeletal pain (**see [Pain](#)**), frequently a complaint of survivors, can cause fatigue and irritability and can also lead to deconditioning and disordered sleep (Yarnell, 1988). Disturbed sleep contributes to daytime sleepiness and fatiguability. Many medications, such as narcotics and benzodiazepines, when used long term for chronic pain, disturb the restful phase of sleep and can contribute to a feeling of fatigue and irritability. Fatigue also can be attributed to medications (**see [Medications](#)**), such as beta blockers, or excessive use of alcohol or marijuana. Deconditioning is another contributing factor to general fatigue. It can lead to disuse atrophy and new weakness of muscles, as well as reduced cardiovascular fitness (Stanghelle et al., 1993). Polio survivors may take three to four times longer to convalesce from illness, surgery, or trauma, compared to individuals who have a full complement of anterior horn cells. While staying in condition is important, each survivor must find the balance between overworking their delicate old reinnervated motor units and appropriate conditioning exercise (**see [Exercise](#)**).

Respiratory problems contribute to fatigue. Polio survivors may have obstructive or central sleep apnea (**see [Sleep Apnea](#)**) causing daytime sleepiness and fatigue. Survivors with increased respiratory muscle weakness may develop carbon dioxide (CO₂) retention due to shallow breathing, especially at night. CO₂ narcosis leads to fatigue and sleepiness during the day resulting in napping during conversations or periods of mild relaxation (**see [Underventilation](#)**).

Dealing with additional disability is emotionally draining for many and can lead to depression (**see [Depression](#)**) with decreased attention and concentration, or distractibility (Backman, 1987). Sadness and/or grieving for lost function (**see [Loss](#)**), as well as depression, can cause fatigue.

Finally, there is the theory that some polio survivors have fatigue as a result of having had polioencephalitis. These individuals may experience a sense of central fatiguability (decreased attention and concentration and memory loss) due to involvement of various brain structures including the reticular activating system (Bruno et al., 1991).

To adequately treat the symptom of fatigue, the various contributing factors need to be identified. Fatigue due to complications of chronic pain, deconditioning, medications, depression, or breathing problems, or fatigue due to dysfunction of the motor units (**see [Weakness](#)**) must be treated appropriately.

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THE IRS VISITS APPA!



By Cheryl Hollis

On Saturday, September 10, 2011 APPA heard from Ms. Alicia Allen, a Stakeholder Liaison Advocate with the Internal Revenue Service, who presented our program with an emphasis on tax benefits for disabled taxpayers and senior citizens. A plethora of information was shared that is listed as follows:

Publication 17 (pub. 17) is known as the 'IRS Bible'. It can be found online, at any IRS location or you can call 800-829-1040 and one will be mailed to you.

Tax Payer Assistance Centers in our area are at:

401 West Peachtree St., NW, Atlanta (in the Summit Building)

1899 Powers Ferry Road, Smyrna

2888 Woodcock Boulevard (near the I-85 and Chamblee-Tucker Road intersection)

The IRS has a vast presence online. You can find them on:

www.irs.gov where you can research different tabs or use a topic search, Twitter,

FaceBook (mainly for professionals),

www.irsvideos.gov for webinars and other forums,

YouTube clips on IRS tax related topics,

an application, *IRS2go*, for smart phones,

Podcasts on iTunes,

www.Disability.gov.

Different publications (known as 'pub') were highlighted:

Pub. 17 – the IRS "Bible"

Pub. 3966 – Living and Working with Disabilities

Pub. 907 – Tax Highlights for Persons with Disabilities

Continued on next page

Pub. 524 – Credit for the Elderly or the Disabled

Pub. 554 – Tax Guide for Seniors

Each of these publications is available online at

www.IRS.gov, at any IRS location or by calling toll free 800-829-3676.

Free tax return preparation for taxpayers who qualify can be utilized through: the Volunteer Income Tax Assistance Program (VITA) for low to moderate income (generally, \$49,000 and below). In Georgia these sites are located in Savannah, Athens, Atlanta, and Hinesville. the Tax Counseling for the Elderly (TCE) program in conjunction with AARP for people aged 60 and older. Call 1-800-829-1040 for more information.

The forms and publication for tax year 2011 are not available until a later date, however, the information for tax year 2010 can help us get started in the right direction.

APPA wishes to thank Ms. Allen for taking time out of a beautiful Saturday afternoon to bring us this information.

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

Vernon Jenkins

Marie Latta

Phyllis McCarthy

Pat Jenkins

Anonymous

Anonymous

Dick & Anita Weir

Thank You!!!!!!!



Discounts



APPA NEWS knows times are tough!

It seems to cost more and more every time you go anywhere to buy anything. In keeping with our tradition of helping our readers any way we can we are pleased to present you with a new feature. **The Discount List!** In this issue we have restaurant discounts for you. In future issues we'll have grocery, travel, and others. These haven't been verified but it never hurts to ask if they offer any senior discount!!

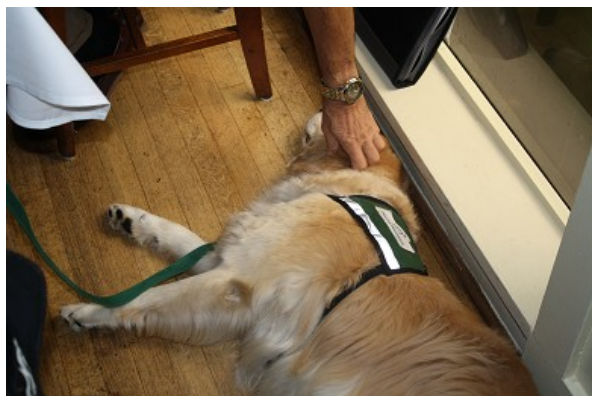
- Applebee's: 15% off with Golden Apple Card (60+)
- Arby's: 10% off (55+)
- Ben & Jerry's: 10% off (60+)
- Bennigan's: discount varies by location
- Bob's Big Boy: discount varies by location (60+)
- Boston Market: 10% off (65+)
- Burger King: 10% off (60+)
- Captain D's Seafood: discount varies on location (62+)
- Chick-Fil-A: 10% off or free small drink or coffee (55+)
- Chili's: 10% off (55+)
- CiCi's Pizza: 10% off (60+)
- Culver's: 10% off (60+)
- Denny's: 10% off, 20% off for AARP members (55+)
- Dunkin' Donuts: 10% off or free coffee (55+)
- Einstein's Bagels: 10% off baker's dozen of bagels (60+)
- Fuddrucker's: 10% off any senior platter (55+)
- Gatti's Pizza: 10% off (60+)
- Golden Corral: 10% off (60+)
- Hardee's: \$0.33 beverages everyday (65+)

- IHOP: 10% off (55+)
- Jack in the Box: up to 20% off (55+)
- KFC: free small drink with any meal (55+)
- Krispy Kreme: 10% off (50+)
- Long John Silver's: various discounts at participating locations (55+)
- McDonald's: discounts on coffee everyday (55+)
- Mrs. Fields: 10% off at participating locations (60+)
- Shoney's: 10% off
- Sonic: 10% off or free beverage (60+)
- Steak 'n Shake: 10% off every Monday & Tuesday (50+)
- Subway: 10% off (60+)
- Sweet Tomatoes 10% off (62+)
- Taco Bell: 5% off; free beverages for seniors (65+)
- TCBY: 10% off (55+)
- Tea Room Cafe: 10% off (50+)
- Village Inn: 10% off (60+)
- Waffle House: 10% off every Monday (60+)
- Wendy's: 10% off (55+)
- White Castle: 10% off (62+)

Editors note: Many thanks to Barbara Reynolds for letting me know about these discounts!!

BINGO!!!!

On Saturday, August 6, 2011 APPA resumed their monthly meeting after a summer break in July. A gathering was planned for *Joey D's Steak and Seafood* near Perimeter Mall where the after lunch delight was one of APPA's renowned Bingo events. With a total of 15 gift cards almost everyone left with a prize. Once again APPA's resident Bingo Mistress, Vicki Crowell, kept things rolling. Many thanks to Vicki for providing everything necessary and volunteering as our 'caller'. If you missed this meeting make plans for our next Bingo party (whenever that may be) as it's always a favorite.



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In Memoriam

Suzanne Verret



ATLANTA
FEBRUARY 17-19, 2012

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They are mentioned simply as a public service to polio survivors and those interested in them.

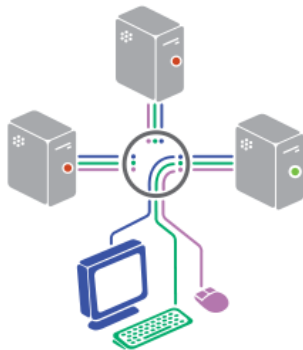
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The information provided herein represents what the authors believe they heard during presentations at **APPA**. The authors are neither legally or medically trained and for these reasons may not have recorded an accurate accounting or understanding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

Tech Bits & Bytes

By Joe Drogan

Sometimes technology and nature actually come together. After a particularly arduous move of the “Penguin Labs” facilities from what is now a lovely dining room into a room of its own I am really enjoying having a real separate office to work in. I have found that getting the computers off by themselves, away from distractions like the TV, has made a huge difference in the way I use them. When I’m in the office I’m working. When I’m not I’m not. I still sit out on the front porch with my Android phone or netbook browsing, emailing, and some research, but the serious stuff gets done in the office. Sometimes however it’s nice to have a little front porch office experience. The other day I was writing an article on a really relaxing rainy day. I wanted to listen to the rain while I was in the office. The main system here is a monster. It’s got a fancy processor, state of the art video processor, four fans to keep everything cool and is pretty noisy. So I wanted to work on the netbook because it’s whisper quiet. I type a lot better on the hi-tech keyboard attached to the monster though. It’s a Logitech G15, an awesome product on its own with keyboard macros and shortcuts. It even lights up so nontouch typists like me can type with the lights low. In addition I wanted to use the big monitor the monster has and the special mouse with the shortcut buttons on it too. Enter something called the KVM switch. KVM stands for **K**eyboard, **V**ideo, and **M**ouse.



TRENDnet KVM Switch



Belkin SOHO KVM Switch

What it allows you to do is have multiple computers hooked together to share one keyboard, monitor and mouse. Newer ones like mine allow you to share speakers and microphones too. So I was able to hear the rain thru the window and work on the quiet netbook with all the comforts of the big system. Today I’m writing this while I listen to the birdies at the feeders. Some KVM switches can work in reverse mode too. That means multiple monitors with one ‘puter. That’s a southern term meanin’ computer;-) Yeah I’ll get letters on that one! Why would you need to do that? Well for instance you might have a Netflix type of system goin’ where you download shows and want to see them on the big screen TV. Sooo

Continued on next page

when the computer download is done the KVM can be switched from the computer monitor to the big screen TV in the other room. KVM's like everything else in technology come in various flavors. Simple ones with 2 ports are around \$15 on up to 8 port ones that get way up there around \$700. When I was setting mine up I tried several until I found one with the features and performance I wanted. For most things I recommend a store that will easily allow you to exchange or get a refund. I like Fry's. I have purchased bunches of items from them and returned/exchanged quite a few too. Their 30 day return policy is great and you can find people there that actually know what they are talking about. I have the SOHO KVM Switch shown by Belkin and have used products by a little company called TRENDnet that have been surprisingly solid and dirt cheap. So to summarize, by utilizing a KVM switch I can write this article on a netbook at the beach, then easily switch to the large monitor and fancy keyboard and mouse in the office to lay out the graphics and pictures and all for this issue of **APPA NEWS**.

Wonder if they make a switch that'll "switch" me back to the beach at Tybee Island! 😊



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



Disclaimer: The author has no affiliation with any of the companies mentioned financial or otherwise.



14th Annual Disability Day

February 16, 2012

Disability Day at the Capitol

Disability Day at the Capitol is an extraordinary event where people with disabilities, their families and advocates for disabilities rights rally together at the Georgia Capitol steps with state lawmakers and supporters from across Georgia. The event is sponsored by the Georgia Council on Developmental Disabilities (GCDD). It is the largest annual public gathering held during the official legislative session. **More than 2,000 supporters** from across the state are expected each year for a day of advocacy activities.

MEMBERSHIP IN APPAReturn TO: **APPA**, P. O. Box 250566, Atlanta, GA 30325**DATE** ___ / ___ / ___Make checks payable to: **APPA**Individual ☐ \$20 Family ☐ \$40 Corporate ☐ \$75 Lifetime ☐ \$400 Additional Contribution _____

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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?

- | | |
|--|---|
| <input type="checkbox"/> Membership outreach (phone calls to shut-ins) | <input type="checkbox"/> Newsletter (write articles, proofread) |
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| | <input type="checkbox"/> Program planning |
| | <input type="checkbox"/> Assist with answering APPA phone line |

Llp/10-2006

APPA UPCOMING EVENTS

December 3 **Holiday Party** at
 94 Perimeter Center West
 Perimeter Mall, Atlanta, GA

WILDFIRE
STEAKS, CHOPS & SEAFOOD

2012 Meeting Dates

January Winter Break	August 4
February 4	September 8 (2nd Sat due to Labor Day holiday)
March 3	October 6 (due to Columbus Day holiday - 10/8)
April 14 (Easter is 1st weekend)	November 3
May 5	December 1
June 2	
July Summer Break	



Atlanta Post-Polio Association

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Lee Hughey	Newsletter Proofreader
Gene Seay	Newsletter Proofreader

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Thanks, Your **APPA** Board

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Association

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