

Atlanta Post-Polio Association

APPA News

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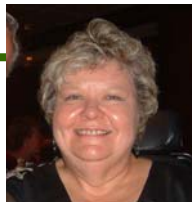
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April - June 2007



Message From The President

Much is happening in APPA and it is an exciting time to be a part of it all. Our Care Team effort is in full swing, our holiday party was a huge success and our first meeting of the year was one of the best we have ever had. We've received a grant in the amount of \$3,000 from the March of Dimes and a grant for \$2,500 from the Governor's

Council on Developmental Disabilities. Your Board of Directors is working diligently to make this the best year yet for APPA members.

It is my honor to have another opportunity to be your President. I want each of you to feel that you are served by APPA. In turn, I want to create an atmosphere in which you will have an opportunity to serve your fellow polio survivors. An Unknown Author wrote "Lessons From Geese" which best describes my attitude about the coming year.

Lessons From Geese . . .

As each bird flaps his wings, it creates an uplift for others behind him. There is 71% more flying range in V-formation than in flying alone.

Lesson: People who share a common direction and sense of purpose can get there quicker.

Whenever a goose flies out of formation, he quickly feels the drag and tries to get back into position.

Lesson: It's harder to do some things alone than together.

When the lead goose gets tired, he rotates back into the formation and another goose flies ahead.

Lesson: Shared leadership and interdependence gives us each a chance to lead as well as an opportunity to rest.

The geese in formation honk from behind to encourage those up front to keep up the pace.

Lesson: We need to make sure our honking is encouraging; not discouraging.

When a goose gets sick or wounded and falls, two geese fall out and stay with her until she revives or dies. Then they catch up or join another flock.

Lesson: Stand by your colleagues in difficult times as well as in good.

Let us keep these lessons close to us as we work to support all our friends in APPA.

By Linda Priest

NEW WEBSITE ADDRESS: www.atlantapostpolio.com



POST-POLIO HEALTH INTERNATIONAL AWARDS RESEARCH GRANT TO UNIVERSITY OF ARKANSAS TEAM



Post-Polio Health International's fourth research grant has been awarded to the University of Arkansas in the amount of \$25,000. The researchers propose to determine whether there is a unique signature, or disease biomarker, in the immune system of individuals with post-polio syndrome (PPS) that would enable a more definitive diagnosis of PPS.

PPS is a slowly progressive neurodegenerative disease that occurs many years later in individuals previously affected by paralytic poliomyelitis due to the poliovirus infection. The causes of PPS are unknown but it is characterized primarily by new muscle weakness that negatively affects the quality of life of survivors.

Biomarkers are biological measures found associated with specific diseases. They are useful because they can assist in disease diagnosis or provide a means of monitoring disease development and progression.

The researchers at UAMS recently detected the increased presence of a distinct immune cell population in the blood of individuals with PPS but not healthy individuals, although the number of donors examined was small. The detected cells represent a recently described subtype of T cells, known as regulatory T cells (Tregs). The research award from Post-Polio Health International will

fund a small pilot study that will determine whether development of PPS is associated with increased numbers of Tregs and whether the Tregs found in individuals with PPS have unusual properties as compared with those in healthy individuals.

Principal Investigator Dr. Rahnuma Wahid said, "We are very grateful to PHI for their support of this research. Although the research is in its very early stages and our initial results need to be rigorously tested in a much larger group of individuals with PPS, a biomarker for PPS that can be potentially measured in an individual's blood should enable a more rapid and more definitive diagnosis of this debilitating disease." said Postdoctoral Research Assistant, Microbiology and Immunology Department, at the University of Arkansas for Medical Sciences.

Joan L. Headley, executive director of Post-Polio Health International, said "A definitive diagnosis of PPS is difficult because it is based on past history, which may be lost or incomplete, or dependent on recall. The diagnosis is complex and unreliable because many symptoms of PPS overlap those of other diseases including osteoarthritis, fibromyalgia, hypothyroidism and a number of neurological conditions. Because available treatments are limited, finding a definitive test for PPS would not only help with a diagnosis but would also help develop potentially more effective thera-

pies. Post-Polio Health International's Research Fund was established in 1995 to seek scientific information leading to eventual amelioration of the consequences of poliomyelitis and/or neuromuscular respiratory diseases. This is the fourth grant to be awarded. Complete reports on the first three research studies:

- ***Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life***
- ***Women With Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress***
- ***Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis***

are available on Post-Polio Health International's website, www.post-polio.org (click on Research).

Post-Polio Health International actively promotes education, research, advocacy and networking among the post-polio community to enhance the lives and independence of polio survivors and home ventilator users.

Don't Forget APPA Dues

**January 1, 2007
Membership Form
on Page 11**



ASK DR. PERRY . . .

Reported by Mary Clarke Atwood

Rancho Los Amigos Post-Polio Support Group Newsletter-May 2006

Editorial assistance by V. Duboucheron, J. Perry, M.D.

Updated March 2006 © Copyright 2006 Mary Clarke Atwood, Reprint permission ranchospsg@hotmail.com

Our thanks to Dr. Perry for so graciously taking the time to review and update these responses. Since retiring after 40 years of dedicated, full time county service, polio specialist Dr. Jacquelin Perry continues her work at Rancho but in a new capacity -- as a volunteer consultant. The Rancho Los Amigos Post-Polio clinic continues to be a source of excellent care each Friday afternoon due to the commitment of two other excellent physicians. Dr. Sophia Chun is the current chief of the clinic; her medical training includes both internal medicine and rehabilitation. Dr. Vance Eberly is an orthopedic surgeon. Both attend the clinic regularly and Dr. Perry is there frequently. Dr. Perry also volunteers as a medical consultant to the Rancho Los Amigos Pathokinesiology Laboratory. She no longer gives lectures.

Continued on page 4

Care Team Effort Under Way

Our new Care Team Project is well under way. We have APPA members categorized by their home/geographical area. If you haven't received a call, you will shortly. A Care Team Leader will be calling at least once a month to check on how you are doing, and to give you updated information about APPA meetings. In turn, you will be instructed to call them if you have anything you would like to discuss about polio or if you have a need/request such as a hospitalization, death in the family, etc.

We want to be more connected to our membership, but we realize that not everyone can make it to our meetings. Our hope is that this will give us an opportunity to serve each other in a more tangible way.

Charlotte Terry, our Care Team Captain, has taken on the

enormous task of keeping in touch with Care Team Leaders and keeping me informed if there are problems that need attention. Gloria Powell is her able assistant. I want to take this opportunity to thank them for their hard work, and to thank the following who have volunteered to serve as Care Team Leaders:

- Sally Yocum
- Karen Sebastian
- Judy Dance
- Ann Coultrip
- Jean Kropa
- Cheryl Hollis (she volunteered to take two lists!!!)
- Shirley Duhart-Green
- Nancy Truluck
- Brenda Maddox
- Barbara Forest
- Alice Felton
- Patricia Emerson (she also took two lists!!!)

We still need three people willing to give a little of their time.



The nice thing about this job is that you can do it from home. We need someone to call people in the Duluth-Buford--Cumming area, the Lawrenceville-Grayson area, and the Norcross-Chamblee area.

Please let Charlotte know at 404 -875-1060 if you can volunteer for this worthwhile assignment.

Introducing Our Newest Board Member - In Her Own Words



**Karen
Sebastian
APPA
Phone Line**

When I was 4 years old, my two sisters and I came down with acute polio symptoms. Although my sisters were able to fully recover, I was paralyzed from my neck down. After six months in a Detroit-area hospital, I came home with full leg braces and crutches. My attitude was "OK, I am BACK in business!" Determined to do everything my sisters did, I succeeded by asking myself one question . . . not "Can I do this?" but "How can I do this?" Eventually I wore only one full leg brace and seldom used crutches. My mother told me not to let other kids play with my crutches. Regardless, I so enjoyed delegating who could play with my crutches during recess. I tried to be fair, giving

everyone equal opportunities.

I went to college, earned a master's degree in Speech and Language Therapy, married and worked in the public school systems of MI and GA. I worked half time when I had my kids, a daughter (now 24) and a son (19). Because of my son's learning disabilities and other special needs, I spent a lot of time and energy advocating for services for him and others in the school system. At about age 43 I began losing strength in my strong leg and feeling increasing fatigue and muscular pain. After 26 years of teaching, I was forced to retire, although I continued volunteering as Special

Ed. advocate to help other parents navigate the red tape involved in obtaining adequate support services in the school system.

Eventually, my marriage ended, after 28 years and increasing post-polio problems severely limited my ability to function, even in daily activities. Currently, I have daily fatigue, pain and mobility problems. Many days I am not able to be productive at all. I'm hoping that moving to a wheelchair-accessible home in May will make life easier. Although I struggle with depression at times, I still stand behind positive thinking. My favorite quote is: "Whether you think you can or you think you can't, you're right." -- Henry Ford

ASK DR. PERRY . . . continued from page 3

Question: Are you familiar with electro-stimulation for polio survivors?

Answer: The answer is yes and the answer is no. The easiest way to stimulate a muscle is to use one that has a nerve. Therefore, this involves the nerve-muscle junction. Electro-stimulation has been tried on a few polio survivors at Rancho with no affect; Dr. Halstead, a polio survivor affiliated with National Rehabilitation Hospital in Washington, D.C., tried it on himself with no affect; several of Dr. Perry's patients tried it at Dr. Pape's office in Canada with no affect. So electro-stimulation is not an answer. Post-polio patients' problems are with the nerves.

Exercise: Some researchers in other parts of the country favor exercise for certain polio survivors. I observed that their research has been done in parts of the country that have bad weather -- so their subjects already have about 3 months disuse due to climate. Here in Southern California we do not have disuse because of bad weather. If disuse of muscles does exist, then exercise may be needed. But if there is no disuse, such as here in Southern California, exercise is not indicated.

Question: Does spinal stenosis occur earlier for polio survivors?

Answer: Spinal stenosis is the thickening of bone around the spinal canal. It does occur in natural society but it is not very common. I have not seen any PPS patients with spinal stenosis.

This will be a recurring column. So look for it in upcoming issues.



MARIE'S VOICE

by Marie Latta

Marie's stirring up dust in Sandy Springs! I have lived in Sandy Springs since 1995 when I had to sell my steps. (I lived in an upstairs flat in Tucker.) I found Sandy Springs to be a difficult community in which to make friends. And like too many of our Metro Atlanta communities and neighborhoods, the pedestrian access was (and still is) almost non-existent. I have told the city council that I live on an island with no bridge to the community.

On February 11, 2007, the Atlanta Journal Constitution did a feature story on my advocacy work in Sandy Springs. They even put a slide show online. Here's the scoop if you want to take a peek.

Story: <http://www.ajc.com/metro/content/metro/northfulton/stories/2007/02/12/0211nfxlatta.html>

Photos: <http://lpe.ajc.com/>

Marie's twin tubes update. Since I have dubbed the feeding tube the unruly child and the trach the good child, I'll refer to them that way. The unruly child has calmed down a great deal. After I had it changed in September and figured out how to stop the flow from the leaky port on the new one with a bread bag twister, I haven't had any tube falling out incidents. When I had the tube checked by my GI doctor recently, he marveled at how clean it was. I thanked him, but I really wanted to say, "It would have been nice if you had taught me how to care for it instead of my having a 6 month learning curve getting it under control."

What about the good child? I would never have understood how easy it is to care for the trach if I had not had the feeding tube as comparison. I have scrapped the idea of a stainless steel tube which had been recommended by my (then) ENT and others. My tube is a size 8. Dr. Kenny had said absolutely not to go lower than a 6. The ENT wanted to place a size 4 stainless steel. I was told by a respiratory therapist at Shepherd that a scope would not even fit in a size 4. And I also discovered that a standard universal fitting which allows for oxygen and other little things to be connected to the trach in an emergency is not available. Dr. Zadoff's advice, that I should use what works for me took all the stress off. Dr. Zadoff goes into the "good guys" category along with Dr. Kenny and Dr. Leslie.

What difference have the tubes made? A world of difference. I am nutritionally so much better off. All of the health/nutritional levels they draw blood to test for are in a strong normal range. And I am so happy to find breathing an easy thing to do. I feel stronger and just all around healthier. The really exiting news is that since January I can wear my voice valve. I am guessing it is because I am stronger and have very little secretion. I don't feel that suffocating resistance I did the first few months.

And what about the challenges? I still have my ever-present post polio fatigue, but the degree has really lessened. And I don't feel or sound like I'm going to give out of air any minute. The new challenge is that I am having some overuse stress in my hands, primarily from all the feeding tube regimen. An occupational therapist is helping me sort things out and figure out different ways to do things. I have stopped using the plunger. That means I get to wait for the speed of

gravity for my formula to crawl its way through the small opening of the tube into my stomach. God has all sorts of ways to keep reteaching us patience!

Staying strong into the future. I have recently gotten speech therapy and am getting OT and PT to learn new ways to keep all my muscles awake. It has been wonderful. If you are wondering about speech, I've learned oral exercises that make me use my muscles in my head and throat. Yes, I even exercise my tongue (Have a good laugh!!). To activate muscles all over my body, we are using stretching and isometric exercises. I do it all from my chair or lying down. It has helped me so much overall that I've begun thinking there needs to be an overall program of stretching and isometric exercises for polio survivors. This is not just for when we are having trouble, but it helps keep unused muscles active.

We should all pat ourselves on the back for being bold enough, and dare we say pushy, to keep asking questions and putting the brakes on when medical folks make decisions that would be bad for us. Look around you and your community. What are your biggest community needs? And what are your medical care providers not doing for you personally that you think they should? Now that you have decided on your priorities, jump into the fray. Be an advocate for yourself and others. Even as we manage our fatigue, I hope we can always find ways to speak out, to make a difference. For the sake of all of us, we must have a voice. I believe that the boldness of polio survivors will help masses of people who are afraid to speak up. Cheers for life, breath, and a voice!

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LATTA@mindspring.com

KNOWLEDGE IS POWER: Wills, Trusts and Powers of Attorney by Ron Swor

APPA's guest speaker for the February meeting was William J. White, Attorney-at-Law and CPA. Mr. White is an expert in securing the health care and estate wishes of his clients using the legal instruments of Wills, Powers of Attorneys, Living Wills, and Trusts.

Mr. White began his presentation stating his role is to assist clients in developing "Directives." These Directives specifically define what the client's personal representative (s) will decide for them regarding health care, life and death matters, and the protection and distribution of their estate (financial, property and other assets) before they die and afterwards. In this manner the client's designated representative protects the various interests of the client by closely adhering to the instructions of the client to be implemented during the time when the client is unable to act in their own behalf. Thus, these legal instruments prevent others (family members, friends, doctors or hospital staff) from acting counter to the wishes of the client.

When registering to enter a hospital today the hospital staff will request the patient's "Advanced Directives." In essence, these Directives spell out for the hospital their instructions if you become unable to tell them your preferences on your own. These "Advanced Directives" serve to direct the hospital to the person you designated to state your healthcare and life and death wishes. This is what a Living Will provides. These Directives prevent the doctors and/or hospitals from making critical decisions for the patient or refusing to make a decision. The Terry Schiavo case in Florida highlighted the importance of Living Wills and advance health care directives. For 15 years Mrs. Schiavo, who did not have a living will to protect her and experienced extensive brain damage in 1990, was kept alive by being placed on a feeding tube. Her doctor refused to disconnect the feeding tube. This type of life and death issue can be avoided using the legal instruments indicated above and a knowledgeable attorney to properly create them. Mr. White emphasized that everyone has the right to control all aspects of their personal care and medical treatment. This can be accomplished by legally assigning the responsibility to someone to act in your behalf (an Agent in Fact) if you become disabled, incapacitated or incompetent. Living Wills and Durable Power of Attorney (DPOA) are the instruments that serve to document your wishes in these matters. While a Living Will expresses your wishes when you are in a vegetative state, a DPOA is employed to control your overall health care when you cannot act on your own. Here the Agent in Fact (or Attorney in Fact) is empowered to act for you. These agents have the power to admit or discharge you from the hospital care. A provision can be added, if so desired, that a doctor will help your designated representative in reaching a decision. There are basically three options for the DPOA: 1) Keep you alive no matter what the situation, 2) Do not take any special effort to keep you alive (this is like a Living Will), and 3) If the quality of life is not worth living, cut you off feeding or breathing tubes. The key here is to prevent you from being at the mercy of doctor or a hospital regarding important health care matters.

In Mr. White's opinion every person needs both a Living Will and DPOA. As a safeguard, an alternative representative should be designated. However, do not make your representative a committee of two or more to avoid conflicts of opinion. An alternate is needed if the first designated representative is unavailable for any reason. He offered that if you are admitted at the hospital without an Agent in Fact, you could get a physician to sign for you. However, he recommended that you make the effort to have these matters covered in advance for your own protection.

It should be noted that a Will and a DPOA are separate from a "Do Not Resuscitate (DNR)" order. A DNR tells medical professionals not to perform CPR if your breathing and heartbeat ceases.

Having a Will for you and your spouse is for your mutual protection. A Will defines the disposition of one's personal and jointly owned assets after death. It also names an Executor who is allowed to transfer title of property and other holdings. The Executor can be the remaining spouse, any family member or an attorney. At the time of death, the Executor can gain access to a Safety Deposit Box to obtain the original version of the Will by providing a Death Certificate and showing a copy of the Will. With the Death Certificate and the Will, the Court



will issue a Letter of Testamentary giving the Executor permission to take possession of the contents of the Deposit Box and authority for transferring title of property and to act on other matters of the estate as defined in the Will. Mr. White gave an example of a person that took a Georgia Will form from an Internet web site. That person made the mistake of having it witness by the family members who are affected by the Will. When this error was found at the time of his death, the Will was declared invalid and the estate had to be probated by a court-assigned administrator.

Not having a Will leaves the door open to having someone completely unknown named by the court to act as In testate Administrator. This person receives compensation from the estate for their work in resolving the issues of the estate and the process can be very slow in getting financial and property matters resolved. This situation should be avoided.

Mr. White also stated that a Trust could be included within a Will. For example, one can transfer property to a Trust. You have to name a Trustee, who is not related, to handle the Trust and protect it for the intended purpose. That Trustee works for a fee and allocates the money or property according to directions specified in the Trust. A person with two families may use this option to properly allocate the estate assets among all family members. There is something called a Spendthrift Trust that is used when you need someone to protect your property against creditors. If the Trustee is a bank or corporation the fees can be as high as 5% (Georgia State law) and a minimum estate value must be met. Banks will not negotiate on the fee. Long term Trusts require corporate Trustees, however. All of these matters can get very complicated to those not trained in the law. For this reason professional help should be sought.

There is a Financial Power of Attorney (FPOA) that one would use to handle financial affairs during a period of time when you are unable to do it for yourself. For example, an extended hospital stay may prohibit taking care of routine business matters. The designated person would write checks to pay bills, conduct dealings with a bank, and negotiate with insurance companies. A condition specifying that a designated person act only if you are unable to act on your own can be made. It could also be tied into a doctor's pronouncement before initiating.

A question was asked regarding whether a Will was needed really if one's estate was less than the 2.5 million dollar limit. Mr. White responded that you couldn't always count on this to be the case. He gave an example of a person who died because of an aircraft accident. The insurance settlement raised the value of the estate significantly higher. This situation led to high Probate costs to process the estate.

Pertaining to the various legal instruments discussed, Mr. White recommended that a competent attorney prepare these documents. In this manner attorneys will explain options, prepare the documents and properly witness them before a Notary. Attorneys normally maintain copies of a Will, DPOA or other documents in the event they get misplaced.

APPA was very grateful to Mr. White for volunteering to enlighten its members on these important personal protection issues. Mr. White can be reached at his Tucker office at 404-320-9811.

Meeting Handouts included: Living Wills and Durable Powers of Attorney for Health Care Wills, Selecting a Personal Care Home, Selecting a Nursing Home,

These handouts are a part of the State Bar of Georgia Consumer Pamphlet Series and can be found at www.gabar.org/sections/section_web_pages/fiduciary_law

William J. White, Attorney-at-Law, 3760 Lavista Road, Suite 200, Tucker, GA 30084, 404-320-9811 bweagle@bellsouth.net

Disclaimer: The information provided herein represents what the author believes he heard during the February 17 presentation. The author is neither legally trained nor an expert in the personal protection legal instruments indicated in the summary. For this reason the author may not have recorded an accurate accounting or understanding of the important details discussed. For these reasons, neither he 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 Attorney at Law before attempting to establish a Will, Living Will or Power of Attorney on your own. It is hoped that this summary serves to apprise the reader of the need for these legal personal protection instruments.

SOCIAL SCENE

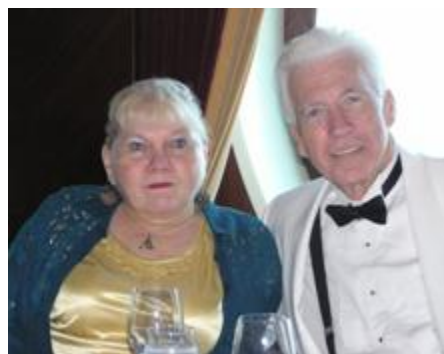


***APPA Friends
and Family
Gather in 2006
For a Fun-Filled
Western
Caribbean
Cruise***



***There is
Something For
Everyone ...***

***The Party
Animals ...***



***The Super
Tourist ...***



***If interested in
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**The Best
Part About
Cruising is
Someone Else
Does The
Cooking**

YEAH !



**2006
Great
Summer
Social**



***This Year's Social June 9th
For Details See Page 11***

The Market Place



Invacare Power Wheelchair, Storm Series, Ranger X...\$1000

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**To Place An Add
Contact**

Barbara Reynolds at breynol@bellsouth.net

Upcoming Events



International Polio Conference Update and Panel Discussion



April 28th, 1:00 PM, Emory Rehabilitation Center

Our April meeting will include a panel discussion by APPA members who attended the recent International Polio Conference in Miami. Handouts from the conference will be provided. Following the program, there will be a brief business meeting. The APPA Board will provide a year-end report and discussion of the 2006 budget. The Board will be available to answer your questions about our goals and plans for 2007.

APPA Annual Social, June 9th 2:00 PM Lunch & Bingo Party

Johnny Carino's Italian Restaurant
3330 Camp Creek, East Point 30344
(404) 494-3000 or www.carinos.com

RSVP to Cheryl Hollis: ToC_P_H@bellsouth.net

Meeting Shepherd Center August 2007 TBA

MEMBERSHIP IN APPA

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Make checks payable to: APPA

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

Name (s) _____

Address _____

City State Zip _____

Telephone _____

Email Address _____

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.

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.

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, proof read) |
| <input type="checkbox"/> Public Relations | <input type="checkbox"/> Fundraising |
| <input type="checkbox"/> Data base assistance | <input type="checkbox"/> APPA phone tree help |
| <input type="checkbox"/> Planning a conference | <input type="checkbox"/> Assist with social events |
| | <input type="checkbox"/> Program planning |
| | <input type="checkbox"/> Assist with answering APPA phone line |

Obituaries

APPA Members who served us well:

Gus Petitt . . . Past Board Member, Past Editor, Past Database Manager
Cathy Bruce . . . Past Board Member, Past President
Frank Leakey

Be Sure to Attend APPA's Annual Business Meeting April 28, 2007

After the International Polio Conference presentation at our next meeting, we will have a brief Business Meeting. The APPA Board will provide a report on APPA business, our 2006 budget and answer your questions about our goals and plans. Don't miss the Annual APPA Business Meeting , April 28th, 1:00 PM, Emory Rehabilitation Center.

◆ ◆ ◆ ◆ Friendly Reminder ◆ ◆ ◆

**Make sure your APPA dues are paid ASAP
so you will be included in the next APPA Directory.**

Atlanta Post Polio Association

APPA News

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