



American Parkinson Disease Association  
Georgia Chapter and  
The Information and Referral Center  
at Emory University  
P.O. Box 49416  
Atlanta, GA 30359

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# MARK YOUR CALENDAR!

The next educational meetings located at Budd Terrace Auditorium on the Wesley Woods Center Campus are as follows:

## February 16, 2007

Alternative Therapies in PD by *Dr. Jorge Juncos*

## March 15, 2007

Ask the Doctor by *Dr. Stewart Factor*

## April 19, 2007

The Genetics of Parkinson's Disease;  
What Do We Know & What Are The Implications.  
By *Ami Rosen MS, CGC. Certified Genetic Counselor*

## MAY

*The May meeting is cancelled due to the Caregiver Conference*

**Educational meetings will start at 10:30am. Please come prepared with your questions.**

### OTHER EVENTS:

## March 8-10, 2008

4th Annual Golf Tournament

## April 17, 2008

3rd Annual Concourse Event

## May 15, 2008

Caregiver Conference with Keynote speaker *Lonnie Ali*



*This newsletter made possible by an educational grant from Boehringer Ingelheim*

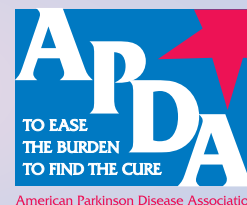
### DISCLAIMER

The material in this newsletter is presented solely for the information of the reader. It is not intended for treatment purposes, but rather for discussion with the patient's physician.

# Parkinson's @ Us

## Newsletter

WINTER / SPRING 2008



**A Publication of the Georgia Chapter, American Parkinson Disease Association, Inc. and The Information & Referral Center at Emory University**

## What is Up with Creatine in Parkinson's Disease

Jorge L Juncos, MD, Medical Director,  
APDA Information and Referral Center

As many of you know, there is a major ongoing trial of creatine monohydrate (creatine) supplementation in Parkinson's disease (PD) sponsored by the National Institutes of Health. Because the study started more than a year ago, we thought that this would be a good time to remind our members of the importance of this trial and that Emory is still recruiting participants.

The importance of the trial stems from the fact that it is the largest trial to date to examine the role of strategies aimed at augmenting energy metabolism in slowing symptom progression in PD. The trial is based in part on the results of an earlier, smaller "futility study" that suggested that the progression of motor symptoms in early, untreated patients receiving creatine may be slower than that in patients treated with placebo (NINDS NET-PD Investigators 2006). This potentially *disease modifying effect* of creatine was at least as strong as that reported with coenzyme Q<sub>10</sub> in PD by Shults et al in 2002. The study is also important because creatine so far has proven safe in most patients and is already easily available.

Unlike the usual drugs used to treat the symptoms in PD, creatine does not improve tremor or mobility in PD. The large doses of creatine (10 grams/day) used in this study are to assure that enough gets into the brain to affect cellular function. In the study we cannot directly measure the fate of dopamine neurons. Instead we measure what is presumed to be an index of dopamine cell survival, that is, progression of parkinsonian symptoms. Compared to the above "futility study" in early patients, the question for this study is: Is the disease modifying effect of creatine robust enough to be measurable in patients already on drug therapy?

Patients who qualify for the study must have been diagnosed with PD in the last 5 years and received treatment for less than 2. During enrollment subjects are assigned to receive creatine or placebo under blind conditions (i.e., neither the subject nor the investigator knows the treatment assignment). During the 5 years of the study patients will continue antiparkinsonian treatment as usual. Based on the general population that has been using creatine supplements for years, and on the few published trials of creatine in PD, it appears that creatine is well tolerated with few subject experiencing cramping, bloating and other intestinal symptoms.

From a scientific standpoint, what do we know about creatine and why do we think it may be helpful in PD? From a developmental perspective, we know creatine is essential to brain development because a number of hereditary errors in creatine or phosphorylcreatine metabolism can result in various forms of mental retardation in children. Dietary creatine is most commonly found in meat containing products. Oral supplementation has been shown to augment brain levels.

From a degenerative perspective, creatine has been shown to protect neurons from damage induced by toxins or mutations used in experimental models of PD, Huntington's disease and amyotrophic lateral sclerosis (Lou Gehrig's disease). Adequate supplies of creatine are essential to the body's capacity to produce metabolic energy. Creatine and phosphorylcreatine serve as an energy buffer by facilitating the transfer of high energy phosphoryl groups to adenosine diphosphate (ADP) to form adenosine triphosphate (ATP). ATP is the all important 'currency' of cellular energy metabolism. The internal (endogenous) production of creatine consumes a significant amount of cellular energy. It requires the activity of enzymes that synthesize creatine from the amino acids arginine, glycine and methionine. Under conditions of marginal energy stores it is reasoned that an external surplus of creatine could result in substantial cellular energy savings. The improved energy balance could then be available to correct other energy depleting processes linked to dopamine cell death. The main two are oxidative stress and mitochondrial dysfunction. Oxidative stress is especially notable in dopamine neurons due to their high content of dopamine and melanin, both of which are highly vulnerable to oxidation reactions. *Oxidative stress* is the cellular equivalent "rusting with aging". In this sense creatine acts as an antioxidant.

Parkinson patients appear to reach a critical level of brain energy depletion as they age. When combined with other genetic and environmental factors, this depletion sets the stage for predisposed individuals to develop PD. The aim of creatine supplementation is thus to keep the presumed marginal stores of creatine in PD from compromising the survival of dopamine neurons. Unlike children with the above metabolic defects, there is no evidence that the creatine/creatine kinase/ phosphorylcreatine pathways are abnormal in PD. This offers the added hope that patients PD will respond to creatine supplementation.

For more information on this study, visit <http://www.parkinsontrial.ninds.nih.gov/>, email [info@parkinsontrial.org](mailto:info@parkinsontrial.org), or call (404) 728-4982.

## Georgia Chapter Executive Committee

**Annemarie Schwarzkopf**  
President

**Kelli Rogan, CFP, CIMA,**  
Vice President

**Patti Klein**  
Treasurer

**Victoria Collier**  
Secretary

**Glenn Rapp**  
Young PD Rep

**Carol Palmer**  
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Member at Large

**Jessica Gill**  
Member at Large

**Ajay Koduri**  
Member at Large

**Eileen Piasecki RN, LCSW**  
Member at Large

**Lynn Ross LMSW**  
Member at Large

**John Thames**  
Member at Large

**APDA Georgia Chapter**  
P. O. Box 49416  
Atlanta, GA 30359  
404-325-2020  
[www.apdageorgia.org](http://www.apdageorgia.org)

## Emory I & R Center Staff

**Jorge L. Juncos, M.D.**  
Medical Director

**Mary Louise Weeks**  
R.N., B.S.N Coordinator

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Atlanta, GA 30329  
404-728-6552

## Newsletter Staff

**Mary Louise Weeks**  
R.N., B.S.N  
Editor

**Linda McGinn, R.N.**  
Copy Editor

## President's Corner

*As your newly-installed President I would like to take this opportunity to tell you a little bit about myself.*

*My life, so far, has been a wonderful series of experiences in the United States and in Europe. My parents are both from Austria but they emigrated (with me!) several decades ago and now live here in the Atlanta area. I have lived and worked in Germany, Austria and the USA – a checkered career that includes banking, advertising, foreign exchange student management and now my present career as Elder Care advisor for A Place for Mom. In this capacity I counsel people who need to find care for elderly loved ones. I can help them find assisted living, dementia care, and in-home care in the Atlanta area. I am also a middle-aged mom of a college student!*

*I am very grateful to Carol Palmer for recruiting me and for “teaching me the ropes” for the past year as I served as your Vice President. I look forward to continuing her fine work.*

*Our eyes are now focused on the upcoming Annual Golf Tournament/Dinner (March 2008). Please help us find sponsors, participants and prizes for our live auction. This is our most important fundraiser of the year! We need your help to make sure it is a success.*

*Visit our website for more information on all our activities and opportunities. And if you want to “chat” with me, just give me a call on my cell phone: 404-290-9596. I look forward to getting to know you.*

**Annemarie Schwarzkopf**  
President

## Gainesville Support Group

We are known as the Lake Country Shakers and we serve 10 counties in NE GA.. Our group will be 13 years old next February; we have 49 members and an average attendance of 33. We meet at the St. Paul United Methodist Church, 404 Washington St., Gainesville, GA 30501. Our meetings are held on the first and third Thursdays of each month at 11:00AM; we meet for an hour and 15 minutes but our people begin coming by 10:00AM and often stay and visit with one another until 1:00PM or after. We are a traditional support group where we share concerns, solutions and information. Occasionally we have a speaker. Dr DeLong has spoken to our group.

Following our gathering, refreshments and announcements, we divide into two groups, one for caregivers and the other for patients. Caregivers, especially, find this support system most helpful. Ours is a highly cohesive group and very welcoming of newcomers.

Because PD patients tend to isolate, we offer many social opportunities. We go on day trips as well as more extended travels. Recently, 11 of us spent four days and three nights in Charleston; to celebrate Thanksgiving, 32 of us shared a meal at the Carriage House Restaurant in Jefferson. Our Christmas party was held December 13th. What a turnout we had!

Leaders of the group are Marie and Bob Bridges, 770-532-8848, email: [marienbob@bellsouth.net](mailto:marienbob@bellsouth.net). and Louell and Ray Roper, 678-546-5455.



# 4th annual Golf tournament

*Smoke Rise Golf & Country Club*

**March 8-10, 2008**

Saturday, March 8th - Dinner/Live Auction  
Sunday & Monday

March 9 & 10th - 2 day golf tournament

*Limited availability on Sunday.*

**Please get your teams registered early**

*To register please contact:*

Kathy Edwards 404-325-2020 or

Edward\_k@bellsouth.net.

*The Georgia Chapter of the*

**American Parkinson Disease Association**

*Cordially invites you to attend a*

**Dinner & Live Auction**

**March 8, 2008**

6:30 -9:30 pm

**Smoke Rise Golf & Country Club**

4900 Chedworth Drive,

Stone Mountain, GA

**\$125.00 per couple**

**\$75.00 per individual**

**\$600.00 table of 10**

*Net proceeds to benefit APDA  
Georgia Programs & Services*



*Parkinson's & Us*

### **Dinner/Live Auction Reservations**

**Sat., March 8, 2008, Smoke Rise Golf & Country Club**

*Please respond by March 3, 2008. Seating is limited.*

**Yes, I will be attending the event and wish to make:**

\_\_\_\_\_ reservation(s) at \$125.00 a couple = \$ \_\_\_\_\_ enclosed, or

\_\_\_\_\_ reservation(s) at \$600.00 table of 10 = \$ \_\_\_\_\_ enclosed, or

\_\_\_\_\_ reservation at \$75.00 for 1 individual = \$ \_\_\_\_\_ enclosed.

*I will be unable to attend, but enclosed is my contribution for \$ \_\_\_\_\_*

*Make checks payable to: APDA Georgia Chapter, PO Box 49416, Atl., GA 30359*

Check \$ \_\_\_\_\_ Charge \$ \_\_\_\_\_  VISA  MC  AmEx  Discover

Card # \_\_\_\_\_ Exp. \_\_\_\_\_ Signature \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_ Please seat me with \_\_\_\_\_

# Third Annual Concourse Benefit for Parkinson's

*We Cordially invite  
you to attend*

**The Third Annual  
Concourse Benefit for Parkinson's**  
Thursday Evening  
**April 17, 2008**  
from 6:00 until 9:00 p.m.  
at the  
**Concourse Athletic Club**  
in Sandy Springs

**Food, Music  
and dancing  
& More.**

All proceeds go to  
APDA Georgia Chapter

The Third Annual Concourse Benefit for Parkinson's will be held on Thursday evening, April 17, 2008, from 6:00 until 9:00 p.m. This lovely event for approximately 300 people takes place, weather permitting, poolside at the Concourse Athletic Club located in Sandy Springs in the Concourse Office Park at the corner of Hammond Drive and Peachtree-Dunwoody Road. The people of Atlanta know the office park as home to the "King and Queen" towers.

The nearby Carrabba's Italian Ristorante along with Concourse Athletic Club, is sponsoring food and beverages. Each year the menu seems even more impressive than the one before. Features of the evening include Carrabba's heavy hors d'oeuvres, two free glasses of wine or beer per ticket, music by a well-known live band through the evening, dancing around the pool and an opportunity to participate in a raffle and a fabulous silent auction.

*Volunteers are needed to help with the event, both before and during the party. All proceeds go to APDA Georgia Chapter.* Please plan to come on April 17th to this fun and fabulous party that greatly benefits the Parkinson's community. **To volunteer please contact Kathy Edwards at 404-325-2020**

## NEW Billboards!



Mr. Bill Wilkins, chairman of Wilkins Media Company, implemented the APDA'S first outdoor advertising program in December. This program consisting of three outdoor bulletins will reach over 300,000 people daily in the Atlanta metropolitan market. The value of the media space in this program exceeds \$70,000 and was provided pro bono by Wilkins Media and Lamar Advertising. The Wilkins team designed the billboard with the APDA logo, and the Information and Referral phone number in hopes of reaching more Parkinson Disease patients and their families while increasing public awareness. The billboards will be rotated around the metro Atlanta area in a total of 15 different locations. Be sure to look for our billboards along the highways!

## Meet Your NEW 2008 Chapter Board Members.

### Ajay Koduri - Member at Large

Ajay Koduri is an attorney in the Franchise Group of the Atlanta office of DLA Piper US LLP. Ajay has a J.D from Vanderbilt University Law School and a B.S. from Duke University. Ajay is part of the APDA because he would like to become more involved in the Atlanta community and to contribute towards Parkinson's disease research and cure.

### Eileen Piasecki, RN, LCSW - Member at Large

Eileen Piasecki began her professional career as an RN working at two VA Medical Centers where she focused primarily on patient education. Many years later, she changed direction slightly and became a licensed clinical social worker interested in group therapy. Eileen currently has a private psychotherapy practice in Sandy Springs and work as needed, at Anchor Hospital in College Park. Two years ago, she became interested in volunteering to do more group work and answered a request for a social worker to facilitate a Young Onset Parkinson's Disease support group. It was shortly after joining this group as a facilitator, that Eileen learned she had the early stages of Parkinson's Disease. Now she feels, "I am a member of this group in every sense of the word!"

Eileen hopes, in joining the Board of the APDA, to add some value to the Georgia chapter with both professional skills as a patient/client advocate, as well as a person, with intimate experience of having Parkinson's Disease.

### Lynn Ross, LMSW - Member at Large

Lynn Ross, LMSW, is a social worker with the Department of Neurology Movement Disorders Program at Emory University. In this position, Lynn assists patients and their families with accessing resources and support within their community. Lynn also provides educational information to patients and their caregivers through facilitating support groups for Huntington's disease and essential tremor. She has a special interest in helping spouses adjust to their role as caregiver to a loved one with a chronic illness. Lynn's experiences as both a formal and a family caregiver are beneficial to her PD patients and their families in her position at Emory.

### John Thames - Member at Large

John Thames is a new board member of the Georgia Chapter of the American Parkinson Disease Association. He was the Family and Community Services Director at the Georgia Chapter of the Alzheimer's Association where he advised families of people with dementia. He currently works at the Community Relations Coordinator of Homewell Senior Care that provides in-home, live-in, and overnight care. John is also a volunteer teacher of English as a second language at the Brookhaven Library in DeKalb County where he has taught classes for the past eight years.

## Time to Make A Difference

On December 8th, 2007 APDA Georgia and Fine Line Gallery celebrated the first annual "Time To Make A Difference" fundraiser for Parkinson's Disease. The idea was the inspiration of Kelly Morgenstern, owner of Fine Line Gallery who donated the space for the party, several of the works of art to be auctioned off and all his energy and enthusiasm. Starting at 6pm that evening we had people arriving to enjoy the wine and appetizers and wander around Kelly's terrific art gallery to admire the art he had on display and especially to admire the 22 clocks that had been created specifically for this event. Kelly had arranged for artists around the country to donate one-of-a-kind art clocks for our Silent Auction. At the end of the evening all party-goers gathered in the room with these beautiful clocks to see which lucky bidder would win which clock. In addition to the Silent Auction the highlight of the evening was the raffle for Kelly's original painting, "A New Beginning". We wish to thank Kelly for his dedication to our cause and suggest that our members go visit his lovely gallery:

*Parkinson's @ Us*



### Fine Line Gallery

465 Boulevard SE,  
Atlanta, GA 30312

404-624-3900 [www.finelinegallery.net](http://www.finelinegallery.net)

# SEVERE MEDICAID CHANGES . . . & How They Affect YOU!

Medicaid is a benefit to individuals who live in nursing homes and cannot afford to pay the private rate for that care. Both the federal government as well as the state of Georgia contribute to the individual's care to ensure their health care needs are being met.

Due to budget crises, cuts are continually being made at both levels of government. Medicaid is increasingly becoming difficult to obtain, even by the most destitute. Below is a summary of the most critical changes.

## 2007 Medicaid Eligibility Resource Limits

* Single Individual	\$2,000
* Married Couple, both seeking Benefits	\$3,000
* Married Couple, only one seeking Benefits	\$103,640

## FEDERAL LAW CHANGES

### I. Deficit Reduction Act of 2005

#### A. Medicaid Transfer of Resources Look-Back Period

If a person gives away property, money or assets of any kind to another person who is not their spouse, a transfer of assets penalty will be assessed and the person who made the gift will not qualify for Medicaid for a period of time because of the transfer. The "Look-Back Period" for transfers changed from three years to FIVE years (60 months). The effective date of this change is February 8, 2006. All transfers of assets that were accomplished before February 8, 2006 will be subject to the old three-year look-back rules. However, any transfer made on or after February 8, 2006 will be subject to the harsher look-back period of five years. The penalty applies to gifts made to churches and also for special occasions, such as birthdays and Christmas.

#### B. Annuities

People who are seeking Medicaid and who own annuities that were purchased by the individual (as opposed to purchased by an employer) and are not held as part of an individual retirement plan (inside of an IRA), will be subject to new Medicaid laws.

The applicant for assistance must disclose any interest the individual or the spouse has in an annuity. The Medicaid applicant/recipient must declare that the State will be named as either the first beneficiary of the annuity or the second beneficiary behind a spouse, a minor child, or a child who is disabled. The annuity must be irrevocable, non-assignable, actuarially sound, is making equal payments (on a monthly basis) during the term of the annuity without any deferrals and no balloon payments.

EVEN IF all of those requirements have been met, the State of Georgia will still count the annuity as a countable asset to eligibility purposes. Thus, it does not benefit anyone to have an annuity if they need or want to rely on Medicaid benefits for long term care.

#### C. Home Equity

Under the new law, an individual who resides in a skilled nursing facility and who applies for Medicaid assistance may not qualify for benefits if they own a home. The new law states, an individual shall not be eligible for nursing facility services or other long-term care services if the individual's equity interest in the home exceeds \$500,000. If the equity interest is below \$500,000, then the house remains an exempt resource for eligibility purposes. This law shall not apply to individuals who have a spouse, minor child, or child with disabilities who lives in the home.

## GEORGIA SPECIFIC CHANGES

### A. Previously Exempt Assets Now Countable

#### 1. Automobiles

Only one exempt vehicle per household. However, if the Medicaid applicant is single, the automobile may still be a countable resource unless the applicant can establish the following: is title in applicant's name only; who uses the auto; where is the auto parked; can the applicant's or representative provide times and dates the automobile was used to transport the applicant's; is it routinely used by someone else; what is the mileage used compared to the number of miles used to transport the member; was the automobile purchased while the applicant lived in the nursing home or near the time of entering the nursing home; and who holds the policy and pays for the auto insurance.

If it appears that the automobile is rarely used by the applicant's or was purchased to shelter assets, count the auto as a resource.

## 2. Burial Exclusion Allowance:

Life insurance policies, pre-paid burial contracts, burial funds set aside. A Medicaid applicant, and the spouse if there is one, is permitted a \$10,000 burial allowance. The State designates an hierarchy with regard to what is attributed toward the allowance. First, all term life policies owned are attributed towards the burial allowance. If none, then the face value of all whole life policies. If the face values combined are more than \$10,000, then the total cash surrender value of all policies, not used in the burial exclusion allowance, shall be counted as a resource. Assuming the applicant has no insurance or just a small policy, then the state looks at pre-paid burial contracts. Burial space items may be purchased without being attributed toward the \$10,000 limit (casket, marker, etc.). However, the value of funeral services paid in advance are counted toward the \$10,000 exclusion allowance. If the aforementioned is accomplished and does not reach the \$10,000 limit, or if none of the above is done, then a person may set aside \$10,000 in cash assets and designate them for burial. A person cannot set aside a car or the cash surrender value of a life insurance policy for burial. The money set aside for burial cannot be co-mingled with other assets. Once set aside, the money cannot be spent during the Medicaid applicant's life.

## B. Estate Recovery in Georgia

Georgia began implementing Estate Recovery in February 2007. All Medicaid recipients who have received Medicaid for 6 consecutive months, who are over the age of 55, and have an estate over \$25,000 will be subject to Estate Recovery. Recovery of costs paid for by Georgia will be collected from patients who received Medicaid benefits from May 3, 2006 and forward. Thus, for people on Medicaid prior to that date who die after that date, their recovery will be limited to the costs provided for their care as of May 3, 2006 and later. Estate recovery is delayed if the Medicaid recipient has a spouse, minor child, or child with disabilities who is living in the home or using the assets for their own needs.

*If you have questions about any of the above information, you can contact the author, Elder Care Attorney, Victoria L. Collier, at:*

**The Elder & Disability Law Firm of Victoria L. Collier, PC**  
160 Clairemont Ave., Suite 660, Decatur, Georgia 30030, 404-370-0696.

## 10 Tips for Family Caregivers

- Take charge of your life - don't let your loved one's illness or disability always take center stage.
- Remember to be good to yourself. Maintain your own health through exercise, nutrition, and proper rest. Take time to do the things you enjoy and maintain contact with friends and family.
- Watch out for signs of depression and don't delay in getting professional help when you need it.
- When people offer to help, accept the offer and suggest specific things they can do.
- Educate yourself about your loved one's condition. Information is empowering.
- There is a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
- Trust your instincts. Most of the time, they'll lead you in the right direction.
- Grieve for your losses and then allow yourself to dream new dreams.
- Stand up for your rights as a caregiver and a citizen.
- Seek support from other caregivers. Consider attending a support group or program for family caregivers. There is great strength in knowing you are not alone.

## APDA Georgia Chapter mourns the loss of a past president

Ronald M. Dillon died at Georgia War Veteran's Nursing Home in Augusta, GA on Wednesday, October 17th after a 30 year courageous battle with Parkinson's Disease.

Mr. Dillon was born and raised in Rockaway Beach, NY. In 1978 he moved with his family to Marietta, GA. Ron retired in 1988 after 32 years with Burlington Industries where he was a regional sales manager in the textile division. Upon retirement he became active in the Georgia Chapter of American Parkinson's Disease Association and was the second president of the chapter for 6 years. He instituted many fund raising activities funded by corporations with whom he had been involved and raised many thousands of dollars for research and education for Parkinson's Disease. Ron was the one who started the first walkathon held on the grounds of Wesley Woods in 1990. To quote Joel Gerstel from the National office, "Ron put the Atlanta Chapter on the map!" He served in the United States Army and was a veteran of the Korean War. He will always be remembered for his great humor, charm and positive attitude.