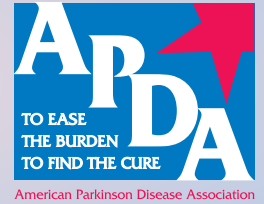


# Parkinson's @ Us

## Newsletter

Winter 2009



**A Publication of the American Parkinson Disease Association  
Information and Referral Center at Emory University and the APDA Georgia Chapter**

## **VA EXTENDS “AGENT ORANGE” BENEFITS TO MORE VETERANS**

### *Parkinson's Disease, Two Other Illnesses Recognized*

WASHINGTON –Relying on an independent study by the Institute of Medicine (IOM), Secretary of Veterans Affairs Eric K. Shinseki decided to establish a service-connection for Vietnam Veterans with three specific illnesses based on the latest evidence of an association with the herbicides referred to Agent Orange.

The illnesses affected by the recent decision are B cell leukemias, such as hairy cell leukemia; Parkinson's disease; and ischemic heart disease.

Used in Vietnam to defoliate trees and remove concealment for the enemy, Agent Orange left a legacy of suffering and disability that continues to the present. Between January 1965 and April 1970, an estimated 2.6 million military personnel who served in Vietnam were potentially exposed to sprayed Agent Orange.

In practical terms, Veterans who served in Vietnam during the war and who have a “presumed” illness don't have to prove an association between their illnesses and their military service. This “presumption” simplifies and speeds up the application process for benefits.

The Secretary's decision brings to 15 the number of presumed illnesses recognized by the Department of Veterans Affairs (VA).

“We must do better reviews of illnesses that may be connected to service, and we will,” Shinseki added. “Veterans who endure health problems deserve timely decisions based on solid evidence.”

Other illnesses previously recognized under VA's “presumption” rule as being caused by exposure to herbicides during the Vietnam War are:

- Acute and Subacute Transient Peripheral Neuropathy
- AL Amyloidosis
- Chloracne
- Chronic Lymphocytic Leukemia
- Diabetes Mellitus (Type 2)
- Hodgkin's disease
- Multiple Myeloma
- Non-Hodgkin's Lymphoma
- Porphyria Cutanea Tarda
- Prostate Cancer
- Respiratory Cancers
- Soft Tissue Sarcoma (other than Osteosarcoma, Chondrosarcoma, Kaposi's sarcoma, or Mesothelioma)

Additional information about Agent Orange and VA's services and programs for Veterans exposed to the chemical are available at [www.publichealth.va.gov/exposures/agentorange](http://www.publichealth.va.gov/exposures/agentorange).

# PRESIDENT'S CORNER

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## Newsletter Staff

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

Editor  
Linda McGinn, R.N.  
Copy Editor

Dear Friends,

Our new fiscal year began on August 31, 2009 and we closed the books on last year's efforts. Despite the difficult economic times the Georgia Chapter of APDA was able to maintain its fundraising levels and we look forward to an even better 2010.

Yes, I know I always talk about fundraising – but that is the main focus of our Board of Directors! We are raising the money to support programs for our members and to fund continuing research to find a cure for Parkinson's Disease. As you know our board members all work pro bono for APDA. That, of course, means we can use all the help we can get. Perhaps you know someone who would be an enthusiastic and effective addition to our Board? Please call 404-325-2020 to let us know.

And, again, if you have any suggestions for new programs and services, let us know that too.

Very best wishes,  
Annemarie Schwarzkopf  
President  
Board of Directors  
APDA Georgia Chapter  
[www.apdageorgia.org](http://www.apdageorgia.org)

## URGENT NOTICE

### November Saturday Education Meeting Date Change

The November 21th meeting is being rescheduled

The education meeting has moved to the 2nd Saturday, November 14th

### Dr. Mark Stacy

Director of Movement Disorders at Duke University will be presenting  
Disease Modifying Updates in PD

**Please mark your calendar!!!!!!**

# AMERICAN PARKINSON DISEASE ASSOCIATION (CON'T)

## Support Group Meetings in Georgia and South Carolina

### ATLANTA

APDA Educational Meeting  
Clairmont Oaks  
441 Clairemont Avenue  
Decatur, GA 30030  
3rd Saturday, 10:30 AM (Aug-May)  
Mary Louise Weeks, RN (404) 728-6552

Atypical Parkinsonisms (PSP, MSA, CBD)  
Caregiver Support Group  
Wesley Woods Health Center  
1841 Clifton Road  
Atlanta, GA 30329  
3rd floor conference room  
2nd Saturday, 10:00AM– 11:30AM  
Lynn Ross LMSW 404-728-6300

People with Parkinson's PWP Group  
Westminster Presbyterian Church  
1438 Sheridan Rd. NE  
Atlanta, GA 30324  
3rd Tuesday, 1:00 PM  
MaryAnne Brawley (770) 554-4193

Atlanta Veterans Medical Center  
10th floor, room 110  
1670 Clairmont Road  
Decatur, GA 30033  
1st Tuesday, 1:00- 2:15PM  
Conetta Sam 404-321-6111 x7121

### ATHENS

Athens Council on Aging  
135 Hoyt Street  
Athens, GA 30606  
4th Monday, 2:30 PM  
Chris Hill (706) 549-4850

### BLAIRSVILLE

The Cadence Bank  
Blairsville, GA 30512  
2nd Wednesday, 3:00PM  
Paula Wilde (706) 745-6594  
Peter Schultze (706) 745-9171

### CONYERS

Remington House  
4th Wednesday, 4:00 PM  
Anna Thomas  
(770)787-1796  
ajones3302@amedisys.com

### DOUGLASVILLE

Wellstar Medical Center  
8820 Hospital Drive  
Douglasville, GA 30134  
1st Tuesday, 2:00 PM  
Larry Hennessy (770) 949-9467

### DUNWOODY

EARLY ONSET PD GROUP  
Dunwoody Baptist Church  
1445 Mt. Vernon Road  
Atlanta, Georgia 30338  
3rd Tuesday, 7:00 PM  
Eileen Piasecki (770) 837-9545

Dunwoody United Methodist  
1548 Mt. Vernon Road  
Dunwoody, GA 30338  
2nd Monday, 7:00PM  
Barbara Bean 770-394-0675, ext. 119

### FAYETTEVILLE, NEWNAN, PEACHTREE CITY

Towne Club  
201 Crosstown Road  
Peachtree City, GA 30269  
4th Tuesday, 7:00 PM  
Pam MacAllister (770) 487-4444  
Betty Fry (770) 631-2665

### GAINESVILLE

St. Paul United Methodist Church  
404 Washington St., First Floor  
Gainesville, GA 30501  
First & Third Thursday, 11:00 AM  
Marie and Bob Bridges (770) 532-8848

# AMERICAN PARKINSON DISEASE ASSOCIATION (CON'T)

## Support Group Meetings in Georgia and South Carolina

### GAINESVILLE

Lanier Village Estates  
4511 Misty Morning Way  
Apt 2118  
Gainesville, GA 30506  
2nd Friday, 11:00AM  
Ruth Pearce (770)718-9752

### GRIFFIN

Spalding Regional Medical Center  
601 S. 8th Street  
Griffin, GA 30224  
3rd Thursday, 2:00 PM  
Liz Tarleton, (770)233-2001

### KENNESAW

Kennesaw United Methodist Church  
1810 Ben King Road  
Kennesaw, GA  
2nd Tuesday, 7:00PM  
Juna Crane (770)499-8594  
junacrane@comcast.net  
Maureen Demianyk (770)499-2365  
mdemianyk@hotmail.com

### LAWRENCEVILLE/ GWINNETT

Glancy Rehabilitation Center, Mango Room  
3215 McClure Bridge Road  
Duluth, GA  
2nd Friday, 1:30 PM  
Sharon Hansen (678)312-6175  
shansen@gwinnettmedicalcenter.org

### MACON

Medical Center Wellness Center  
3797 Northside Drive  
Macon, GA 31210 (Sept.-May)  
3rd Thursday, 2:30-3:30PM  
Caregivers 1:30-2:30PM  
Mary Michael Atkinson  
(478)746-9401 x211

### ROME

Fifth Avenue Baptist Church Fellowship Hall  
416 North 5th Avenue  
Rome, GA 30165  
1st Tuesday from 6:00pm - 8:00pm  
James Trussell 706-413-3264  
james@gaparkinsons.org

### ROSWELL

Roswell United Methodist Church  
814 Mimosa Blvd.  
Roswell, GA 30075  
2nd Sunday (Aug. – May), 4:00 PM  
Robin Cleveland, (678)-819-3915  
rcleveland@visitingangels.com

### TIFTON

LeRoy Rogers Senior Center  
315 West 2nd Street  
Tifton, GA 31794  
2nd Tuesday, 2:00 PM (Sept-May)  
Linda Boyette, R.N. (229) 388-1888

### CAREGIVER SUPPORT GROUP

Well Spouse Association  
4th Monday 7-8:30pm  
atlantawsa@gmail.com  
www.freewebs.com/atlantawsa

### SOUTH CAROLINA

#### ANDERSON, SOUTH CAROLINA

AnMed Health Rehabilitation Hospital,  
1 Springback Way  
Activity Room  
3rd Thursday, 2:00 PM  
Katherine Vickerman (864)332-2850

#### CHARLESTON, SC

Bon Secours, St. Francis Hospital  
2095 Henry Tecklenburg Drive,  
Rm 1  
West Ashley, SC 29414  
2nd Sunday at 2:30 pm (except July)  
Gretchen Huff 843-297-1122

# AMERICAN PARKINSON DISEASE ASSOCIATION (CON'T)

## Support Group Meetings in Georgia and South Carolina

### GREENVILLE, SC

John Knox Presbyterian Church  
35 Shannon Dr., Greenville, SC 29615  
3rd Thursday, 2:00 pm (Jan-Nov)  
Sandi Holmes 864-609-1793  
www.parkinsonsupport.org

### HILTON HEAD, SC

HiltonHead Regional Medical Center  
25 Hospital Center Blvd.,  
Hilton Head Island, SC 29926  
3rd Tuesday, at 1:00 pm  
Mary Ann Burgeson 843-757-3776

### LANCASTER, SC

Covenant Baptist Church  
165 Craig Manor Road  
4th Tuesday at 3pm  
Janice Broach 803-285-2014

### MYRTLE BEACH/ MURRELL'S INLET, SC

Waccanaw Community Hospital  
Hwy 17 Murrell's Inlet  
2nd Thursday, 7:00PM  
Elaine Casavant (843) 650-8756

### ROCK CITY, SC

HealthSouth's cafeteria  
1795 Frank Gaston Boulevard (behind Piedmont Medical  
Center) Rock Hill, SC 29732  
3rd Wednesday, 1:30 P.M.  
Valerie Badanich 803-517-4586

### SPARTANBURG, SC

Ballet Spartanburg building of the Chapman Cultural  
Center,  
200 E. St. John Street  
2nd Thursday, 1:30-3:00  
Ethel Perricone (864) 597-1150

### COLUMBIA, SC

Lexington Medical Park Auditorium  
2720 Sunset Boulevard  
West Columbia, SC 29169  
3rd Sunday 3:00PM (July-May)  
Dottie Gantt (803) 604-0061  
lakeside@att.net  
www.columbiaparkinsonsupport.org

### COLUMBIA, SC (Northeast)

The Waterford at Columbia,  
9370 Windsor Lake Blvd.,  
Columbia, SC 29223  
4th Thursday, 12:30 pm  
Paulette L. Freeman, BSW  
803-296-3102

### NORTH CAROLINA

Asheville Chapter  
1st Tuesday 10:30-12:00PM  
Care Partners Health Services  
Seymour Auditorium  
Lisa Laney-Kendrick, MSW  
828-277-4886

If there is not a support group in your area and you would like to start a support group,  
contact the Information and Referral Center at 404-728-6552

# SENIOR CARE COSTS AND GOVERNMENT FUNDING

Article Provided by a Place for Mom

There are government programs that can help if you have a loved one who needs more care than you can provide. Perhaps she needs rehabilitative care after back surgery, or maybe you're pondering nursing home care. When researching senior care costs, it's essential to learn about government resources. The four main sources of government health-related aid—Medicare, Medicaid, PACE, and VA benefits—can help cover some of the senior care costs for your loved one, but usually only under very specific circumstances, and the rules can be dauntingly complex. So we'd like to help you better understand the system by providing this handy guide to how the government programs can help qualified persons pay for their housing and care.



## Medicare

Medicare is the United States largest insurance program, serving individuals aged 65 or older (as well as some disabled people and anyone suffering from end stage renal disease). It has two sections: Part A is also called Hospital Insurance, and Part B is also known as Doctor's Insurance. Medicare Part A is free if a person is entitled to Social Security or Railroad Retirement payments. An individual is

automatically enrolled at age 65. People who do not qualify must pay a premium of \$423 per month in 2008. People aged 65 and older can choose to enroll in Medicare Part B, which is a fee-for-service plan. In 2008, the monthly premium is \$96.40. If an individual doesn't sign up at her first opportunity, enrollment takes place during an annual open-enrollment period. For more information, visit <http://www.medicare.gov/>.

Part A covers some senior care costs in a Skilled Nursing Facility (SNF) after a qualified three-day hospital stay. Patients must enter a Medicare-certified SNF within 30 days of leaving the hospital, and the patient's doctor must order the care. At the SNF:

- Medicare pays for the first 20 days of care
- During days 21 through 100, a patient pays \$128 per day and Medicare pays the rest
- After 100 days, Medicare pays nothing.

Medicare pays for a semiprivate room, meals, skilled nursing and rehabilitative services, and other services and supplies. It does not pay for custodial care, which is defined as care that helps with the activities of daily living, such as dressing, using the bathroom, and eating. All coverage is paid for based on a benefit period, which begins when a patient enters a SNF. The benefit period ends after the patient has not received skilled care in a SNF for 60 days in a row. Once this period ends, a new period begins only after a three-day qualifying hospital stay.

Medicare covers some home health care costs; this is paid for out of both Part A and Part B. Home health care is paid on a prospective payment system for a 60-day episode of care. This episode ends with the close of the first 60 consecutive days in which the patient is not an inpatient in a hospital, SNF, or is not being provided home health services. If an individual is enrolled in both Part A and Part B, this

# SENIOR CARE COSTS AND GOVERNMENT FUNDING (CONT)

Article Provided by a Place for Mom

rate includes all costs for six home health disciplines:

- Skilled nursing services
- Home health aide services
- Physical therapy
- Speech-language pathology services
- Occupational therapy services
- Medical social services

If a patient lives in an assisted living facility (or personal care home, residential home, etc.) that does not primarily engage in providing these six services, Medicare will cover necessary home health care costs for this patient. Once again, Medicare does not pay for custodial care. All services must be ordered by a doctor and provided by a Medicare-certified home care agency. Medicare Part A also covers short-term hospital and inpatient respite care when a terminally-ill patient is under hospice care.

## Medicaid

Medicaid is health insurance that helps pay for medical and long-term care for people with low incomes and resources. Medicaid is a partnership program between the federal and state governments: While states follow set federal guidelines, each state determines some rules and benefits. To qualify, an individual must meet the income and asset guidelines in his state. “Generally, those limits are linked to the federal poverty level, but only as a benchmark. States will set their limits at, above, or below the federal poverty level,” says Mary M. Kahn, a spokeswoman at the Centers for Medicare and Medicaid Services (CMS). For state guidelines, contact a State Medical Assistance office; find this number at [www.medicare.gov/](http://www.medicare.gov/) or call 1-800-MEDICARE. The CMS website, at [www.cms.hhs.gov/](http://www.cms.hhs.gov/), also has individual state rules.

It’s a good idea to enlist the advice of the state

Medicaid office or an attorney before an individual applies for Medicaid. This is partly due to the penalties that can occur when someone “spends down resources.” Often an individual spends down assets to qualify, but rules must be followed during this process. If a person does not initially meet her state’s Medicaid limits, she may still qualify on a month-to-month basis if her medical expenses bring her income level below her state’s eligibility level.

Federal Medicaid laws mandate that states offer nursing home care as a benefit for any enrollee for whom this care is medically necessary. Generally speaking, Medicaid also pays for the following services:

- In adult day care centers, medical services are covered, but custodial care is not covered.
- Respite care can be covered as part of a waiver.
- Home care is available in states that have approved home- and community-based waivers.
- Medical services are covered in group/residential and personal care homes, but custodial care is not covered here.

## PACE

The Program of All-inclusive Care for the Elderly, known as PACE, is an interdisciplinary system that uses Medicare and Medicaid dollars to provide health care. PACE provides the entire continuum of care and services to seniors with chronic care needs, and strives to keep clients living in their homes for as long as possible. To be eligible for PACE, a person must:

- be 55 or older
- be certified as nursing home eligible in his or her state

# SENIOR CARE COSTS AND GOVERNMENT FUNDING (CONT)

Article Provided by a Place for Mom

- live in a PACE service area
- be able to live safely in the community with the support of PACE services.

If your loved one qualifies for Medicaid, dollars from this program pay for part of the PACE premium and Medicare covers the rest. If he doesn't qualify for Medicaid, he must pay a monthly premium to cover the Medicaid portion.

Currently there are 35 PACE providers in 21 states; 20 more providers will be added soon. Four Pre-PACE programs operate under Medicaid contracts, using a fee-for-service for the Medicare-covered services. To find out if an individual lives in a PACE service area, go to [www.npaonline.org/](http://www.npaonline.org/).

PACE delivers a comprehensive set of services focused on the health and well-being of the individual. An interdisciplinary team—including doctors, nurses, social workers, physical and occupational therapists, and drivers—manages each client's care plan. PACE covers senior care costs at the following:

- Nursing home care when a client can no longer live in the community
  - At any given time, 7 or 8 percent of PACE enrollees are permanently in nursing home care.
- Adult day care at PACE day health centers, with transportation provided
- Respite care
- Home care
- Memory care, usually called dementia and Alzheimer's care

Housing in assisted living, residential, or personal care homes isn't usually covered, but PACE often

facilitates the situation of a person living in a more supportive housing environment.

## VA Benefits

Veterans of the United States Armed Forces may be eligible for long-term care services provided by the Department of Veterans Affairs (VA). Eligibility for most health benefits is based on discharge from active military service under other than dishonorable discharge. However, a surviving spouse of a deceased veteran may also be eligible for benefits. To apply for VA health care or determine eligibility, call the VA's Health Benefits Service Center at (877) 222-VETS, or contact a Veterans Benefits Office or VA health care facility (find the nearest location at [www1.va.gov/directory/guide/home.asp](http://www1.va.gov/directory/guide/home.asp)).

The VA offers the following non-institutional care services for veterans:

- An interdisciplinary treatment team provides long-term primary medical care to chronically ill veterans in the Home-based Primary Care program.
- Contract home health care, purchased from private-sector providers at VA medical centers, is also called fee-basis home care.
- Health maintenance and rehabilitative services are offered in Adult Day Health Care programs.
- Veterans who need nursing home care receive community care in the Homemaker and Home Health Aide program.
- Veterans who do not need nursing home care but cannot live independently receive home care in the Community Residential Care Program. The VA only pays for this program's administration and clinical services.
- Respite care in home and community settings is generally limited to 30 days per year.



# SENIOR CARE COSTS AND GOVERNMENT FUNDING (CONT)

Article Provided by a Place for Mom

- In the Geriatric Evaluation and Management program, an interdisciplinary team provides assessment and treatment to older veterans with multiple health, psychosocial, functional, or geriatric issues.
- Some VA facilities have specialized dementia and Alzheimer's care programs, with inpatient and outpatient components.

All of these services may require a co-payment.

The VA also provides nursing home care for eligible veterans. There are three types of nursing homes:

- VA nursing homes usually admit patients that require short-term skilled care, or patients with a service-connected disability.
- State veterans homes have eligibility rules set by the state that runs each home.
- Contract nursing homes meet the needs of veterans who may not qualify for care in the previous types of homes, or if a VA or state home isn't available.

The general rules for nursing home eligibility state that a patient must have a condition that requires inpatient nursing care and be medically stable, and that an appropriate medical provider must assess the patient and confirm the patient needs this care. Social workers at VA medical centers can further explain these qualifications and any co-payment requirements.

## A&A (Aid and Attendance Special Pension)

Veterans and surviving spouses who need the regular attendance of another person to eat, bath, dress, undress, or use the bathroom may qualify for the Aid and Attendance Special Pension (A&A).

Other individuals who qualify include:

- Blind persons,
- Nursing home patients who are mentally or physically incapacitated
- People receiving assisted care in an assisted living facility.

A&A can help pay for senior care costs in the home, nursing home, or assisted living facility. Eligible veterans can receive up to \$1519 per month and an eligible surviving spouse can receive up to \$976 per month; eligible couples can receive up to \$1801 per month. Any wartime Veteran with 90 days of active duty, with one day beginning or ending during a period of War, may apply for A&A. An applicant must also have less than \$80,000 in assets, excluding homes and vehicles. For application information, go to <http://www.veteranaid.org/apply.php>.



# FEAR OF FALLING

By Linda McGinn, R.N.

“We have nothing to fear but fear itself” –Roosevelt’s words have resonated into our lexicon, and are applicable to one of the major concerns of the infirmed and elderly—the fear of falling. As Parkinson’s affects balance and gait, falling is at greater risk, and the body does not cooperate to “catch” the fall. Fear can be magnified, and inactivity becomes a dangerous outcome. As people become scared, they stop doing things, and the immobility can lead to physical deterioration. This leads to greater susceptibility to fall, and the fear feels justified. This cycle can also include withdrawal from social contacts and activities, and subsequent depression. The combination of disease, weakness and depression offers a bleak future with diminishing hope.

It has been estimated that one-third of people over age 65 fall, with 10% of these falls resulting in injury. It is the number one cause of accidental death among this age group. Health professionals now recognize that falls are not a normal part of aging, and that many falls do not need to happen. Environmental risks, such as throw rugs, lack of handrails, wet or icy walks, etc., can be minimized with prudence and planning. Bathrooms

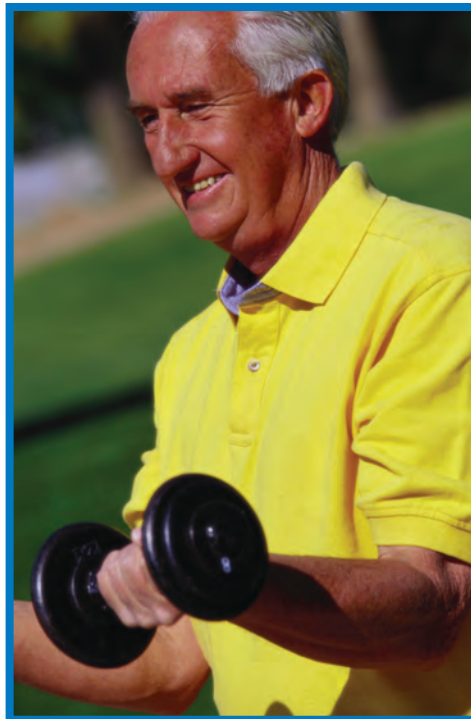
can be modified with support rails, kitchens can be reorganized to alleviate over-reaching for items, non-slip floor tape can be put on tiles that are slippery, and many other techniques can be employed to ensure a safe home. Many books and articles are available for more information on this topic of home safety. The A.A.R.P. website has an excellent article on this subject—under home safety, it is titled “Does

Your Home Meet Your Needs? A Checklist.”

Physical risks can be diminished as well, and the most effective way to accomplish this is exercise. As adults lose 10% of their muscular strength for every decade of life, studies have shown that after a twelve-week exercise program older adults had increased their strength by 30%—equivalent to regaining three decades of lost strength.

Exercise also improves balance, and can improve bone density.

The emotional benefits of exercise are well-lauded, as increased confidence, well-being, and a sense of control result in optimism and happiness. Another technique, learning how to fall, is an injury preventer for the likes of athletes, ice skaters, and paratroopers



## FEAR OF FALLING (CON'T)

By Linda McGinn, R.N.

and these principles can be adapted to the older population. An undergarment has been designed to lessen the impact of falls in the hip area, and these can be viewed at [www.hiprotector.com](http://www.hiprotector.com). For the mobility-impaired, sitting in a wheelchair and using one's legs to propel the wheelchair affords more lower body strength than a motorized scooter. A physical therapist consultation can offer customized, individual plans and direction for these concerns.

But how can the fear be eclipsed? At a seminar for seniors in a New York senior center, the New York Times reported the comments of one senior citizen, Sarah Goldberg, who attended the seminar. She has an "ongoing relationship" with the floor. She figures she averages two or three falls a year. Once, she fell in the shower and lay there for 17 hours until she was discovered. "You name the place," she said "and I've fallen there." She had just fallen a few months ago. Nonetheless, she carries on undeterred. "I worry about falling," she said, "but I don't fear it. I don't restrict my life."

A couple of years ago, she had an occupational

therapist visit her home to make it as fall-proof as possible. Two months ago, she had another assessment to upgrade the safety measures. The toilet was raised, additional handrails were installed, and devices such as a dressing stick, elongated shoehorn and grabber stick were incorporated into her life. She makes a point of doing weight lifting and tai chi at the senior center. As she says, "you shouldn't stop

going on living because you have a fear of falling. Once you restrict your life, your finished. Everything goes. I love life too much for that."

Treating the fear involves awareness and acknowledgment, and incorporating care providers in the discussion. The goal is re-conditioning, and finding the balance between the risk of immobility and mobility.

Another aspect is to identify the reason the fall occurred, and try to correct the cause. In a study done in England, it was suggested that falls could be cut by 50% if post-fall assessments could be done with subsequent corrections made.

Being afraid of injury is a valid concern that shapes our lives; living in fear controls our life. Try to find a healthy regard for gravity, and live accordingly.



# POLO FOR PARKINSON'S 2009 A HUGE SUCCESS!

Wilkins Media Company is proud to announce that the Second Annual Polo for Parkinson's event held on October 11, 2009 was another successful fundraising event for Team Fox and the Michael J. Fox Foundation, despite a reschedule due to Atlanta area flooding on the original date. Weather looked to be an issue again in the week leading up to the event, but on Sunday morning the skies cleared and a beautiful day emerged! Guests enjoyed delicious food and beverages, multiple raffle items, an extensive silent auction, ladies' hat contest and a riveting polo match in which the all-ladies Team Fox team triumphed over the all-male Scuppernon team. A final tally of the day's fundraising is still being compiled, but Wilkins would like to thank attendees and valued sponsors like Solvay Pharmaceuticals, Titan Worldwide, APDA's Georgia Chapter, and Team Cantore (just to name a few!)



## IN MEMORY OF PAUL MAESTRONE

Dr. Gianpaolo “Paul” Maestrone, a worldly man known for his research efforts with Parkinson’s disease, died October 4, 2009 at Staten Island University Hospital, Ocean Breeze. He was 79.

Born in Bergamo, Italy, Dr. Maestrone graduated magna cum laude with a doctor of veterinary medicine degree from the University of Milan, where he became a professor at the age of 23. He first came to the United States in 1953 as a Fulbright Scholar at Iowa State University. He lived in New Brighton until 1956, then lived in Grasmere for 33 years before settling in Dongan Hills 20 years ago.

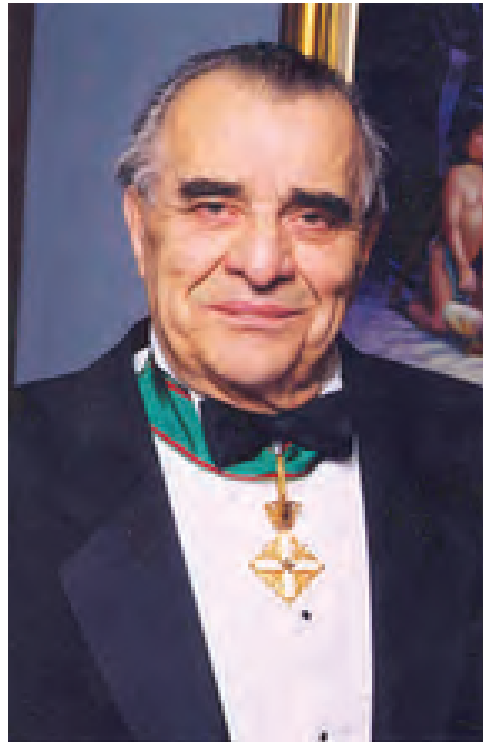
Board certified from the American College of Veterinary Medicine in 1967, Dr. Maestrone held many research positions, starting with the Animal Medical Center in Manhattan for four years, E.R. Squibb in New Brunswick, N.J., for five years and Hoffman-LaRoche, Inc., in Nutley, N.J., for 20 years.

But Dr. Maestrone is mostly known for his deep involvement in Parkinson’s disease research. Following in the footsteps of his father-in-law, who founded the American Parkinson Disease Association, Dr. Maestrone created the Italian Parkinson Disease Association.

He also served for more than 20 years as the director of scientific and medical affairs for the Grasmere-based American Parkinson Disease Association. He was instrumental in developing the World Parkinson Disease Association, the largest such grassroots organization, involving 25 countries and serving 1.5 million Americans with Parkinson’s.

Dr. Maestrone also holds several patents and has authored 50 scientific papers. Among his contributions, he was credited with creating the I & R (Information and Referral) concept, a networking program through which people with Parkinson’s and their families can find information and support. He was instrumental in securing funding for a \$30 million research program about the disease.

He has held memberships with the American Veterinary Medical Association, the American College of Veterinary Microbiology, the New York Academy of Medicine, the American Society for Microbiology, the Theobald Smith Society, the Industrial Veterinarians Association and the Conference of Research Workers in Animal Diseases.



# COENZYME Q10 STUDY

The purpose of this study is to evaluate the safety and effectiveness of high dosages of Coenzyme Q10 in slowing the progression in people who have early Parkinson disease.

You may be eligible if:

- You are 30 years of age or older
- Parkinson's disease was diagnosed within the last 5 years
- Not taking any parkinson's medications

For more information contact: *Barbara Sommerfeld @ 404-728-6944*

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## ABILITIES EXPO: THE NATION'S LEADING EVENT FOR THE DISABILITIES MARKET

For three decades, the major participants in the community of people with disabilities have gathered at Abilities Expo to gain knowledge and improve lives. The end-users, the professionals and the companies whose products and services support this burgeoning market derive tremendous benefit from this impressive event.



Abilities Expo Atlanta 2009 Has Even More to Offer the Community of People with Disabilities. Register Today!



# ADVOCACY – SEEK- SPEAK

By Gilbert Witsell

## Seek Out and Speak Out

I first became aware of Parkinson's disease in the late 1980's when my mother was diagnosed with the disease that took her life in 1988. I didn't become really interested until I was diagnosed in 1997, at which time I began to seek information about this progressively degenerating disease. I sought out educational material through American Parkinson Disease Association, an excellent source for booklets, newsletters, pamphlets and educational seminars which provided the basics of the disease and its treatment. But this isn't enough for me. Living with the disease on a daily basis, knowing it isn't going to get any better, is discouraging. I need for my voice to be heard, and I believe everyone that must live with this debilitating disease, and their caretakers, has the right to be heard on the issues that can help "ease the burden and find a cure".

Too much time passed from 1997 until October 2008 when I attended the Southeastern Parkinson Disease Conference and a presentation of the Parkinson's Action Network – "the unified voice of the Parkinson's disease community." At last here is a place where you can speak out and express your opinion on the major issues of our time regarding Parkinson's disease. PAN gives you the facts of major issues involving PD and provides a communication link, PAN Alerts, to the people empowered to make funding of research possible. These alerts include a prepared request ready to send to your members of Congress, or you can write your own message. You get to speak out on the issues. PAN keeps you informed as matters progress through regular reporting on the legislative impact. Parkinson's Action Network has a Grassroots Advocacy

Program involving thousands, and growing, to make calls, send e-mails and letters to elected officials. "When the people speak, lawmakers listen." There are over 1 million persons living with Parkinson's disease, can you imagine the impact on lawmakers if even 10% of these speak out on the issues? That is what it is all about, make something happen.

## The Unified Voice of the Parkinson's Community

The Parkinson's Action Network (PAN) is the unified education and advocacy voice of the Parkinson's community – fighting to ease the burden and find a cure. Through education and interaction with the Parkinson's community, scientists, policy and opinion leaders, as well as the public at large, PAN advocates for an increased and accelerated investment of public resources to ease the burden and find a cure for the more than 1 million Americans who have Parkinson's disease.

PAN serves as the voice of the Parkinson's community on numerous public policy issues affecting the community. In addition to PAN's work on National Institutes of Health (NIH) funding and research, PAN is a powerful voice on many crucial issues including Parkinson's-specific programs at the U.S. Departments of Defense and Veterans Affairs; Medicare and Social Security; Food and Drug Administration (FDA) drug safety and approval issues; a national Multiple Sclerosis (MS) and Parkinson's disease registry; and PAN's continuing struggle to achieve research freedom for stem cell research.

# ADVOCACY – SEEK- SPEAK (CONT)

By Gilbert Witsell

## Georgia Advocates Needed

By becoming an advocate with PAN, you can make a difference by working with your Members of Congress on public policy issues that are important to the Parkinson's disease community. Contacting your Members of Congress, whether by e-mail, a phone call, or a personal meeting, about the affect Parkinson's disease has on your life is the most effective way to make policy changes. Members of Congress want to hear from their constituents and will listen when you communicate your views.

Becoming an advocate with PAN is easy; sign-up to receive PAN's e-mail Action Alerts. When important Parkinson's issues arise in Congress, PAN e-mails Action Alerts with instructions on how to contact and communicate with your Members of Congress about important legislation. Working together, we will continue to fight for better treatments and a cure for Parkinson's disease.

If you are interested in learning more about the Parkinson's Action Network, please contact James Trussell, Georgia State Coordinator ([james@gaparkinsons.org](mailto:james@gaparkinsons.org) or 706-413-3264) or Gilbert Witsell Georgia District 9 Congressional Coordinator ([gwitsell@bellsouth.net](mailto:gwitsell@bellsouth.net)). In addition to becoming a grassroots advocate for Parkinson Disease, we also have several openings for volunteer Congressional Coordinators in the following congressional districts: District 2 (Rep. Sanford Bishop), District 5 (Rep. John Lewis), District 8 (Rep. Jim Marshall), District 10 (Rep. Paul Broun), District 12 (Rep. John Barrow) and District 13 (Rep. David Scott).

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## SIT AND GET FIT!

This is an exercise program for Parkinson's patients geared towards increasing mobility, balance and strength. Exercise is beneficial for these patients because it can improve neuromuscular awareness, flexibility and joint stiffness, range of motion, coordination, and posture.

University Heights United Methodist Church, 1267 Balsam Dr., Decatur, GA 30033

Tuesdays from 11:30am - 12:15pm

Involves a warm-up/cool-down, light seated workout, mild cardio workout, and lots of strength, balance, posture, and coordination training.

\$90 for nine sessions

Call Kirsten Magee for more info, 678-592-6801 or e-mail at [kdafitness@hotmail.com](mailto:kdafitness@hotmail.com)



# BROOKS & COMPANY DANCE LAUNCHES OUTREACH CLASSES FOR PEOPLE WITH PARKINSON'S DISEASE

This September, brooks & company dance (BCD) launched their Dance for PD classes at the Atlanta Ballet's Center for Dance Education, Cobb Studios. Dance for PD, which offers dance classes free of charge for people with Parkinson's Disease and their caregivers, originated in 2001 in Brooklyn NY through a partnership of the Brooklyn Parkinson Group and the Mark Morris Dance Group. The program focuses on cognitive movement, which has been shown to alleviate tremors for people with Parkinson's Disease.

Joanna Brooks, Artistic Director of BCD and BCD's Executive Management Team, Su Schwenck and Keif Schliefer attended a Dance for PD Workshop in New York with the goal of bringing the program to the Atlanta area. The classes, which are held on the third Thursday of every month, incorporate various dance styles and excerpts from BCD repertory. No dance experience is necessary and participants may use walkers or wheelchairs, if needed.

Brooks is thrilled to be able to bring her training back to Atlanta: "People with Parkinson's Disease assume that dance is the last thing that they imagine themselves doing. To see it happen with grace and fluidity is truly humbling". BCD has plans to expand the program to Southwest Atlanta and to locations outside the Perimeter in the future.

For more information, please call (404) 371- 9652 or visit [www.brooksandcompanydance.org](http://www.brooksandcompanydance.org) or email [info@brooksandcompanydance.org](mailto:info@brooksandcompanydance.org)

**Who:** People with Parkinson's and their caregivers

**Where:** Atlanta Ballet's Center for Dance Education, Cobb Studios, 2000 Windy Hill Rd.

**When:** Third Thursday of every month from 12:30pm to 1:45pm

Classes are free of charge

brooks & company dance, an Atlanta-based modern dance company in its fourth season, creates choreographic work influenced by dance and cultural history, current political and social climates, and the pure joy of movement—often deconstructing the classical canon. brooks & company dance has received Creative Loafing's Best of Atlanta recognition since its inception: 2006 Critics' Pick for "Best Ballet... and Stoning" for The Lottery, 2007 Readers' Pick for Best Dance Performance" for Shorts II, 2009 Readers' Pick for "Best Dance Performance" for CRUX, and 2007 and 2008 Readers' Pick for Best Dance Company."



# DRIVING WITH PARKINSON'S DISEASE

## Driving when you have Parkinson's disease

For most people, driving represents freedom, control and competence. Driving enables most people to get to places they want and need to go. For many people, driving is important economically – some drive as part of their job or to get to and from work.

Driving is a complex skill. our ability to drive safely can be affected by changes in physical, emotional and mental condition. The goal of this brochure is to help you and your health care professional talk about how Parkinson's may affect your ability to drive safely.

## How can Parkinson's disease affect my driving?

Parkinson's disease can cause your arms, hands or legs to shake – even when you are relaxed. It can also make it harder for you to keep your balance, or start to move when you have been still.

If you have Parkinson's and you try to drive, you may not be able to:

- React quickly to a road hazard; or
- Turn the steering wheel; or
- Use the gas pedal or push down the brake

## Can I still drive with Parkinson's?

Most likely, "Yes," in the early stages of the disease, and if you take medicines that control your symptoms.



## What can I do when Parkinson's disease affects my driving

Ask your doctor about medicines and surgeries that could help treat your symptoms of Parkinson's disease. Ask about the effect medicines may have on your continued ability to drive safely.

Staying fit and active will help maintain your muscle strength that you need to drive. This will help keep you safely behind the wheel and on the road.

# DRIVING WITH PARKINSON'S DISEASE (CONT)

Your doctor also can refer you to a center or a specialist who can give you on and off-road tests to see if, and how, your Parkinson's is affecting your driving. The specialist also may offer training to improve your driving skills if your Parkinson's still allows you to drive safely.

Improving your skills should help keep you and others around you safe. To find a specialist near you, call the Association of Driver Rehabilitation Specialist at 1-800-290-2344 or go to their website at [www.aded.net](http://www.aded.net). You also can call your local hospital and rehabilitation facility to find an occupational therapist who can help with the driving skills assessment.

## What if I have to cut back or give up driving?

You can keep your independence even if you have to cut back or give up on your driving. It may take planning ahead on your part, but planning will get you to the places you want to go and the people you want to see.

### Consider:

- Rides with family and friends
- Taxi cabs;
- Shuttle buses or vans;
- Public buses, trains and subways; and
- Walking

Also, senior centers, and religious and other local service groups often offer transportation services for older adults in your community.

## Who can I call for help with transportation?

Call the Eldercare Locator at 1-800-677-1116 and ask for your local Office on Aging, or go to their website at [www.eldercare.gov](http://www.eldercare.gov).

Contact your regional transit authority to find out which bus or train to take.

Call Easter Seals Project ACTION (Accessible Community Transportation In Out Nation) at 1-800-659-6428 or go to their website at [www.projectaction.org](http://www.projectaction.org)





American Parkinson Disease Association  
Information and Referral Center  
at Emory University  
1841 Clifton Road  
Atlanta, GA 30329

Non-Profit Org.  
U.S. Postage  
PAID  
Atlanta, GA  
Permit No. 7992

## **MARK YOUR CALENDAR!**

Upcoming APDA events:

The next Educational Meetings are located at Clairmont Oaks in Decatur, GA

**November 14, 2009**

Disease Modifying Updates in PD by Dr. Mark Stacy

**November 21, 2009**

\*\*\*No meeting\*\*\*

**January 16, 2009**

Vitamins and PD by Marian Evatt, MD

**There will not be an education meeting the month of December we will resume in January**

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

### OTHER EVENTS:



**Monday, March 15, 2010**

Annual Golf Tournament at SmokeRise Country Club

This newsletter made possible by an educational grant from TEVA Neuroscience

### 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.