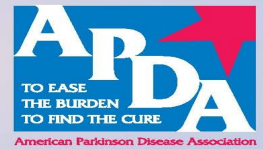


Parkinson's @ Us Newsletter



Fall 2010

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

Racial and Geographic Variation in Parkinson Disease

By Allison Wright Willis, M.D.

Parkinson disease is a common neurodegenerative disease of the elderly with no known cause. My research seeks to identify demographic and environmental factors which may influence who develops PD and who does not. Previously, we did not know how common PD was in the United States, nor did we have extensive data on which people are more likely to develop the disease. Using Medicare data, which is utilized by 98% of Americans over the age of 65, we were able to determine Parkinson disease rates in the United States by race and region of residence.

Below are the highlights from my recently published article in the journal *Neuroepidemiology* (A. W. Willis et al, *Neuroepidemiology* 2010; 34:143-151).

We found that Parkinson disease affects approximately 1.6% of the U.S. population over the age of 65, with about 480,000 people living with the disease at any time. Approximately 130,000 people are newly diagnosed each year. Men are slightly more likely to have the disease, with a male:female ratio of 1.55 (155 men have the disease for every 100 women).

Dr. Willis is an Assistant Professor of Neurology at Washington University School of Medicine. Her clinical areas of expertise include treatment of adults and children with movement disorders; such as Parkinson disease (PD), dystonia and Tourette Syndrome/tics. Her main area of research is in the environmental epidemiology of PD.

PD rates increase with age. White men have a much higher rate of Parkinson disease, up to double that seen in Blacks or Asians. Asian women seem to have the lowest rate of PD in the United States. Geographically, Parkinson disease rates are highest in the Midwest and Northeast regions of our country, where the rates of new and existing cases of Parkinson disease are two to ten times greater than that in the West and South.

There are several interesting theories suggested by this recent study. The finding that Whites have substantially higher rates of Parkinson disease may mean that Blacks and Asians are somehow less susceptible to PD, perhaps due to a protective genetic factor or, to decreased exposure to key environmental factors. The finding that PD is more common in the Midwest and Northeast supports previous research which suggests that non-hereditary PD may be associated with environmental factors (some of which may be pesticides or metals). These areas of the country are hubs of agriculture and industry, and future studies may be able to identify specific environmental factors which raise or lower PD risk.



This article was courtesy of St. Louis APDA Chapter

PRESIDENT'S CORNER

Dear Friends,

First the most important news!!! My dear friend and our GREAT Administrative Manager, Kathy Edwards, is retiring as of the end of this year, 2010. Of course, we (especially me!) are all very sad that she will no longer be in an "official" capacity working for APDA but she has assured me that she is not going anywhere too far away and that she will still be available to me and all of the rest of us for her usual cheery and very helpful advice. Luckily we have found a wonderful person to take over the Administrative Manager position – her name is Barbara Mooney. Many of you may already know Barbara because she has jumped in feet first and has been attending board meetings, committee meetings and educational meetings since August. Please join me in welcoming Barbara to our APDA family!

By the time you receive this newsletter APDA Georgia will have already started our new fiscal year. Like everybody else in this economy we have had to tighten our belt and some of our ambitious ideas are "postponed" until next year....But we continue to provide programs and services to our members and to the general public.

- *We will need a large (expensive) auction item for our upcoming fundraiser*
- *We would like to find a restaurant/fast food place to donate lunches for all our golfers for next year's golf tournament*
- *We need a board member with PR skills*
- *We need help in grant writing*

If you or someone you know can help us with our "wish list" – please call me!

We want to make this organization the best that it can be. Give us your suggestions and check out our website: www.apdageorgia.org

Best wishes,

Annemarie Schwarzkopf
Board President

Support groups offer patients and their families help with day-to-day issues, provide a forum for gathering information about PD, and serve as a place to make new friends who share similar problems.

For a list of support group locations, visit our website at www.apdageorgia.org or call 404-728-6552. Included in this list are specialty groups for Young On-Set and Caregivers. If you are in an area that does not have a support group, call 404-728-6552 and we will help you get the support you need.



YOGA TIME

The Book of Exercise and Yoga for Those with Parkinson's Disease: Using Movement and Meditation to Manage Symptoms (2nd edition).

This first-of-a-kind book outlines a comprehensive program specifically geared to those with Parkinson's disease. It includes chapters on body mechanics/preventing falls, low impact aerobics, strength training, stretching, yoga and Tai Chi exercises to improve posture and balance. It also includes instruction in stress management techniques and information on facial and voice projection exercises.

This book based on the author's 25 years of teaching experience, is a must for those living with Parkinson's disease, their family members and caregivers. The Book of Exercise and Yoga for Those with Parkinson's Disease is for those looking for a complete program to manage the many symptoms of PD and enhance quality of life. The 2nd edition is available in paperback format, contains updated illustrations and an enhanced yoga section including floor exercises. The movements in this book are all explained in detail and illustrated in standing, standing holding onto a chair, and seated variations to accommodate a wide variety of abilities. This complete wellness program goes beyond the traditional exercise book offering information on home safety, fall prevention, activities of daily living, body mechanics (including how to get up from the floor), facial and voice projection exercises as well as information on stress management and relaxation techniques. The goal of these techniques is to help those with Parkinson's disease remain independent.

The book is available through Amazon.com, through the publisher; Create Space <https://www.createpace.com/3462556> or it can be ordered at your local bookstore.

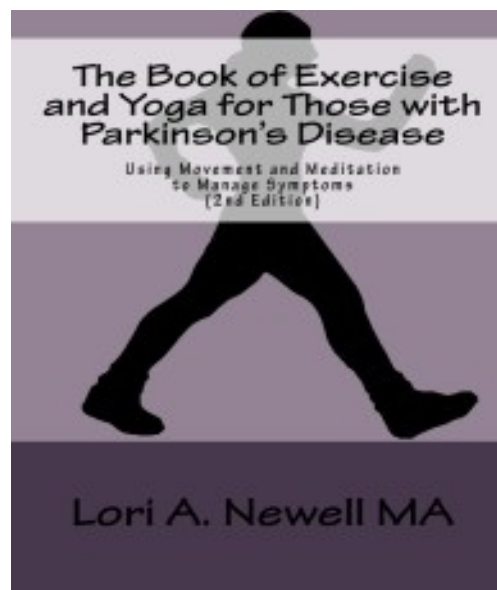
ISBN-13: 978-1453641774. The cost is \$19.95 and proceeds from the sale of this book will be donated to help find a cure for Parkinson's disease.

About the Author

Lori Newell holds a Masters degree in Health Promotion with a concentration in pain and stress management from Norwich University. She is a certified health and fitness instructor through the American College of Sports Medicine, and a certified yoga instructor. She has over 25 years of experience working with individuals, helping them to achieve their health, fitness, and wellness goals. Lori has specialized training in working with those with post-rehabilitative needs, and those with chronic pain and illness. She owns and operates Living Well Yoga and Fitness which offers exercise and wellness programs to a wide variety of populations. Lori also regularly contributes articles to various local and international newsletters, journals and websites.

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APDA Launches First-of-its-Kind Parkinson's Rehab Resource Center

Helping people who have Parkinson's disease (PD) access information on exercise recommendations, the American Parkinson Disease Association (APDA) and Boston University have established the country's first National Resource Center for Rehabilitation.

The center's toll-free "helpline" telephone number is 1-888-606-1688, and callers will be able to speak with a licensed physical therapist who can answer questions about exercise, provide information about programs in the caller's area and provide educational materials.

"Almost a decade ago, APDA successfully led the fight to secure physical therapy coverage for people with PD on Medicare," said Joel Gerstel, executive director of the country's largest grassroots organization serving America's 1.5 million people diagnosed with the progressive, degenerative neurological disease. "At the time, the benefits of exercise and physical therapy were under recognized, but today, exercise has proven a valuable tool in maintaining a healthy lifestyle for people with disease. APDA is again in the forefront by making free physical-exercise information readily available to patients, their caregivers and healthcare professionals across the country," Gerstel said. "Evidence supporting the benefits of exercise for people with Parkinson's disease is growing," said Terry Ellis, PT, PhD, a leader in neurological physical therapy research, and the new center's director.

Dr. Ellis is a clinical associate professor in the department of physical therapy and athletic training at the College of Health and Rehabilitation Sciences: Sargent College. The new resource is an outgrowth of the Center for Neurorehabilitation's Community Wellness Programs, which are exercise programs designed to improve mobility, quality of life and communications for persons with PD. These programs have benefited more than 400 people in 14 New England communities.

Dr. Marie Saint Hilaire, director of the APDA Center for Advanced Research at Boston University, points out the importance of

exercise in the management of Parkinson's disease. "Exercise helps to improve quality of life and day-to-day function in people with Parkinson's disease," said Dr. Saint Hilaire, who recommends that patients with PD consult with a physical therapist early in the disease process in order to reap the benefits right from the start. Vlad Lyczmanenko, president of APDA's Massachusetts Chapter, which is co-funding the center, said that his chapter strongly supports the initiative. "It is imperative that people with PD are first motivated to exercise and then have access to professionals who can help them with practical information about how to exercise correctly for their particular needs." Cathi Thomas, coordinator of the APDA Information & Referral Center at Boston University's Medical Campus, noted the value to other healthcare providers and said the center will maintain updated lists of community rehabilitation specialists. "Our objective is to share this knowledge with patients, caregivers, students and healthcare professionals," said Dr. Ellis. "This partnership with APDA, also known for its pioneering efforts in physical therapy, will give anyone interested an easy, free pathway to the most up-to-date information."

About APDA – www.apdaparkinson.org - With the unique dual mission to "Ease the Burden – Find the Cure," APDA provides support and educational programs for people with Parkinson's disease and their caregivers, and funds scientific research to find the cause(s) and cure for the progressive, degenerative neurological disease. APDA is the country's largest grassroots organization serving America's 1.5 million persons with PD.

About Boston University:

The Center for Neurorehabilitation has a single goal to advance the quality of rehabilitation for those with neurological disorders. The Center offers Physical Therapy, Community Wellness Groups, educational programs and hope for a better quality of life through research-driven improvements in therapy. We're a team of researchers, clinicians and educators with expertise in rehabilitation and movement science. Seldom do clinical practice, advanced research and community programs integrate so well or with such immediate benefits to patients.

VA Publishes Final Regulation to Aid Vietnam Veterans Exposed to Agent Orange

The Department of Veterans Affairs (VA) today, August 31, published its final regulation establishing Parkinson's disease, ischemic heart condition, and B-cell leukemias as service-connected disabilities for Vietnam veterans exposed to Agent Orange. The final regulation grants a 100% disability rating for Parkinson's disease, as well as retroactive veteran and survivor payments for qualifying veterans.

What Does this Mean For Vietnam Vets with PD?

Accessing health care and disability compensation will be easier for qualifying veterans. If a veteran served in Vietnam from January 9, 1962 to May 7, 1975 and now has been diagnosed with Parkinson's disease, they are presumed to have been exposed to herbicides. The veteran does not have to prove an association between their disease and their military service. The presumption simplifies and speeds up the application process for disability compensation, and all those awarded service-connection will become eligible to join the VA healthcare system.

The VA will now review approximately 90,000 previously denied claims by Vietnam veterans for service-connection for these three conditions. Some additional veterans will be eligible for retroactive benefits. For new claims, VA may pay benefits retroactive to the effective date of the regulation or to one year before the date VA receives the application, whichever is later. For pending claims and claims that were previously denied, VA may pay benefits retroactive to the date it received the claim.

So When Will This Go Into Effect?

Even though the final regulation is published, the regulation is subject to a 60-day review period by Congress before the VA can begin paying benefits for new claims.

The Senate Veterans Affairs Committee is scheduled to hold a hearing on September 23 to review the rule and to discuss how the VA Secretary makes his decision to establish a disease as a service-connected disability. There certainly is no intention for Congress to actually block the implementation of the final rule, but the VA will have to wait 60 days before they can start compensating veterans.

What the Final Rule Didn't Do

The Parkinson's community sent nearly 400 comments to the VA in support of the proposed regulation. Many of the comments urged the VA to clarify its definition of Parkinson's to include diseases of Parkinsonism (primary, atypical, and secondary Parkinsonian syndromes). Unfortunately, the final rule did not expand the definition of Parkinson's disease to include Parkinsonism. VA argues that the current medical evidence does not support the expansion of the definition at this time but will reconsider if the Institute of Medicine (IOM) provides additional guidance in future reports.

PAN will continue to work with the VA to ensure that all veterans living with Parkinson's and Parkinsonism receive access to the healthcare and benefits they wholeheartedly deserve.

Apply for Benefits

If you are a Vietnam veteran with Parkinson's and have not applied for benefits, we encourage you to submit your application for compensation now—even before the VA can start paying claims. For more information about applying for VA benefits and Agent Orange, visit the [VA Web site](#).

Andrew Fisher, grandson of Jerry & Toby Zuckman, wrote the following article and poem as a part of his 10th grade Literature assignment.

RATIONAL

The meaning for my topic is to educate others about the disease called Parkinson's Disease and to let one know what it is like to have it. I chose Parkinson's Disease because my grandfather has this disease. Being close to a family member who has this disease truly inspires me to write about it. I decided to write a poem to show passion in words that were short and to the point. I wrote the poem to inspire those who already know about Parkinson and those who do not. My goal was to educate them with strong hearty words. I chose to make my own article to acquaint others with statistics, facts and quotes made by those of people who have Parkinson's Disease first hand ("For the last 15 years or so, it's been physical. I mean, the first part of the battle was the emotional, spiritual to an extent, intellectual. But, having done a lot of that work early on and getting through that battle, it put me in a place where now I just focus on the physical")- Michael J. Fox. Watching my grandfather fight this disease, I realize his struggle. By creating my topic on Parkinson's disease, I hope to reach out to others and show them how it is a difficult disease to handle and with the help of others, this disease may someday have a cure.

Let's Make History

**Everyone has a special person in their life,
A mother, a father, a husband, a wife.
50,000 to 60,000 people are diagnosed each year,
This disease has a habit of being severe.
One may respond, "Then find a cure",
The only problem is that this disease is so obscure.
Loss of balance, shaking, becoming stiff and slow,
One only deserves the right to know.
There is no treatment or cure for this great mystery,
To find one at this point would make history.
A scare to the families who are aware,
They feel as if they are living such despair.
A substantial amount of money for research has been raised,
To help the people we love and praise.
Exercise, eating well and maintaining your health is all we know,
Belief in oneself and one's life will flow.
Don't quit, keep going and without further adieu,
No matter what, we will always love you.**

Upcoming APDA events



Get in the MOOD to help fight Parkinson's Disease -
Lets find a CURE!

WHEN: SATURDAY, SEPTEMBER 25th, 2010

TIME: 7:00 PM -Doors Open

**LOCATION: MOOD LOUNGE
3081 E. SHADOWLAWN AVE
ATLANTA, GA
404.816.1170**

This is a great opportunity for you, your family and friends to join us for an exciting night out at Mood Lounge. Mood Lounge is a European influenced, intimate yet modern experience in Buckhead.

Light refreshments will be served from 7:00 PM to 9:00 PM, and a cash bar. APDA will receive a percentage of the bar sales.

**Valet Parking
NO Cover charge**



2010 Southeastern Parkinson Disease Conference and NATIONAL Young Onset Conference
October 15 - 17, 2010

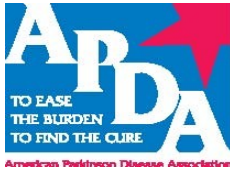
Sheraton Gateway Hotel
Atlanta, Georgia
Registration fee \$79.00 (includes Friday reception, Saturday Breakfast, lunch, dinner & Sunday Breakfast & lunch) visit www.gaparkinsons.org for more information!



Grab those fancy hats and dig out your divot-stomping shoes! Wilkins Media Company and naming sponsor Abbott (formerly Solvay Pharmaceuticals) will be hosting the third-annual Polo for Parkinson's fundraiser event on **Sunday, October 10th at 2pm** at **Chukkar Farm & Polo Club in Alpharetta, GA**. This fun afternoon in Atlanta's beautiful horse country will include an exciting polo match, halftime divot stomp, delicious food, silent auctions, and even a "Best Hat" contest for the ladies. Tickets are \$5 for children 12 and under and \$50 for an adult ticket, which includes unlimited food and drinks (sodas, water, beer & wine). All of the net proceeds from this event will go to Team Fox, the Michael J. Fox Foundation's regional fundraising effort. Of those proceeds, 84% are then allocated to PD research. In the last two years, we've been able to raise almost 155,000! Limited sponsorships are still available. For complete information or to donate, sponsor, or purchase tickets, please visit www.poloformarkinsons.com or call Kathy Bifulco at 770-804-1818.

Sunday, October 10th at 2pm at **Chukkar Farm & Polo Club in Alpharetta, GA**

We hope to See you there!!!



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

Educational Meetings held at Clairmont Oaks:

No meeting in October – See information on Southeastern PD Conference

November 20, 2010 Jeff Hoder, PhD - “Gait and Balance Issues in PD”

No meeting in December

January 15, 2011 To Be Announced

February 19, 2011 Jorge Juncos, MD - “Update on PD 2010-2011, Part 2”

For additional information visit our website at www.apdageorgia.org



APDA GEORGIA CHAPTER IS ON FACEBOOK.

You can send us a friend request or find us by email: Apdageorgia@hotmail.com, or send us an email requesting we add you.

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.