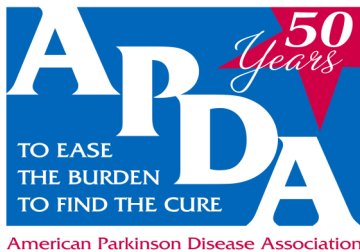


Parkinson's & Us

A Publication of APDA I & R Center and Georgia Chapter

Winter 2014



Punching Out Parkinson's

Delgado's Gym in Sandy Springs is buzzing with activity as nearly two dozen PD Gladiators are having their hands wrapped in preparation for a new fitness class designed for those living with Parkinson's, and sponsored in part by the Georgia Chapters of the American Parkinson Disease Association (APDA) and the National Parkinson's Foundation (NPF).

People with Parkinson's of all ability levels have shown up to participate in a high-intensity boxing workout with the instruction of the Delgado's staff.

I spoke with Larry Kahn, who with his wife, Ellie, have spearheaded the effort to offer a fast-paced, high-energy boxing training class here in the Atlanta area. Similar programs in other cities have generated a buzz in the Parkinson's community as participants have seen positive results in the degree of their symptoms from the practice of the "sweet science," notably Paulie Ayala's class at his gym in Fort Worth, TX, and a similar offering at Scott Newman's Rock Steady Gym in Indianapolis, IN.

Larry tells me that he initially exercised at a normal pace in the first year and a half after his diagnosis. "Then I noticed I was getting a better response with my symptoms from a schedule of high-intensity workouts, several times a week," he says. "One day I woke up and it was cold and my symptoms were bad and it was frustrating. I wanted to hit something", says Larry. Ellie adds, "Imagine if you were to go to sleep and

wake up and you can't use a pen to write." It was then that Larry decided that it was time to reach out to the Atlanta boxing community to offer a class for PD sufferers. He called Paul "The Truth" Delgado (26-12-1, 4 KO), who founded Delgado's Boxing in 2009 and retired professionally in 2012. Paul had heard of the success of Paulie Ayala's class and decided that working with Larry and Ellie to host a class was a great idea, and PD Gladiators was born.

I speak with Paul (who still looks ready to step in the ring) after a high energy class that culminated with a minute of an all-out flurry of punching by the class, with the trainers shouting encouragement. He tells me of his roots in Atlanta (he makes his home here and most of his fights were in Atlanta) and his excitement of being able to work with the community through PD Gladiators. I ask him whether there's much difference working with people with Parkinson's versus other fighters.

"Not really," he tells me. "Every fighter has speedbumps, some are just higher than others. There are similar obstacles. Paul has done his research, too. He tells me of the benefits of high-intensity workouts for people living with Parkinson's, including 5-

time Trainer of the Year Freddie Roach, who has said publicly that he benefits from maintaining a boxing workout regimen. Given the growing body of evidence that suggests that high intensity workouts like boxing have for people with Parkinson's, I ask Paul what he could say to encourage those that still hadn't begun a training regimen to get started: "Ever since I was a little kid, when things got tough I've tried to just keep moving forward. I believe this program can help a lot of people, and it's empowered me. I'd say just get in there." Classes meet on Saturdays at 12 pm at Delgado Boxing Gym, 6335-B Roswell Road, Sandy Springs, GA 30328 (Marshall's Plaza on Roswell between Abernathy and Mt. Vernon). (gloves may be purchased for \$35 from Delgado Boxing). To reserve your free trial in the PD GLADIATORS Boxing Training for PD program or for more information call Delgado Boxing at (404) 856-0093, e-mail info@delgadoboxing.net or pdgladiators@gmail.com or use the contact form at www.pdgladiators.org.



Georgia Chapter

APDA

Executive Board Members

Eric Burkard, CLTC

President

Cheryl Richards-Mann

Secretary

Ed Nichols

Treasurer

Jorge L. Juncos, M.D.

Medical Director

Barbara Mooney

Administrative Manager

Lynn Ross, LMSW

Information & Referral

Center Coordinator

Susan Palmer

Accounting

Ken Alfiero

Member at Large

Katie Beasley Beshara

Member At Large

Jessica Sherrill

Member At Large

APDA Georgia Chapter

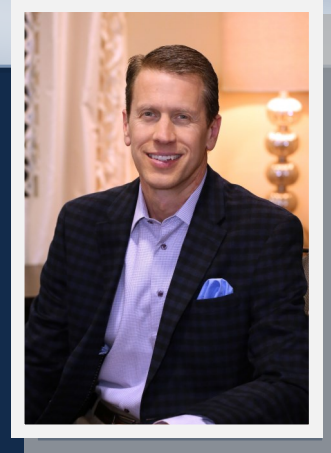
P.O. Box 49416

Atlanta, GA 30359

404-325-2020

www.apdageorgia.org

President's Corner



Dear Friends of APDA,

A most Happy New Year to everyone!

If you have not made your New Year's resolutions yet, I hope you will resolve to make 2014 a year of optimism and movement and also support the many activities, events and initiatives we have planned for the New Year.

A good place to start is the free monthly Education Meetings at Clairmont Oaks in Decatur featuring some of the top clinicians and researchers in Parkinson's in the area and the country. I think you will agree that these meetings are key to empowering everyone to turn information into knowledge and knowledge into action.

I also hope you will take advantage of the new PD-specific exercise programs we are supporting such as Tango dancing, Zumba Gold, Tai Chi through the Yellow River Center and just recently "PD Gladiators", a high intensity, non-contact boxing and conditioning program (see this newsletter for more details). If these programs are not your style, remember, there are several traditional exercise programs in metro Atlanta you can find by clicking the Exercise tab at the top of our website www.apdageorgia.org.

Another area of importance for us is our caregiver assistance program through our partner agencies that provide much needed help to those in difficult financial circumstances. This program does not always take center stage, but it is working effectively to help dozens of needy families throughout the state of Georgia.

On behalf of the board of directors of APDA Georgia Chapter, I wish to extend my heartfelt thanks to all our members and supporters for helping to make these programs possible and in advance for your continued support.

We look forward to hearing your success stories in the New Year!

Warmest regards,

Eric Burkard

APDA Georgia Chapter Gives Back

On February 7th, APDA members participated in a morning of volunteer service at the Atlanta Community Food Bank in downtown Atlanta, one of the largest food banks in the country. Volunteers showed up early for a 3-hour shift to

assist in the important work of sorting, dating and packaging donated food items to be distributed to needy individuals living with food insecurity including seniors and children. It is estimated that 1 out of 5 Georgians is food insecure, meaning they are not sure where they will find their next meal.



APDA Georgia Chapter President Eric Burkard, who organized the morning of service, commented: "The Atlanta Community Food Bank offers a unique opportunity for individuals and groups to give back to the community in a fun and social way while getting some light exercise in the process, something many of our members enjoy doing." All told, APDA's efforts resulted in the packaging of over 9,000 lbs. of food for those in need. The APDA members also signed an APDA T-shirt which will be pinned to the giant ACFB letters on the wall of the Food Bank's Product Rescue Center as evidence of the group's effort that day.

APDA and the Peachtree Road Race

The AJC Peachtree Road Race has distinguished itself as one of the premier Fourth of July traditions in Atlanta with its festive atmosphere, scenic city course and beloved finisher's t-shirt. Organized by the Atlanta Track Club, the largest 10K in the world attracts runners of all ages and paces eager to take part in the Fourth of July tradition. For more information regarding the race go to www.peachtreeroadrace.org.

Registration for the 2014 AJC Peachtree Road Race will open to the public on Saturday, March 15th at www.ajc.com/peachtree. Those wishing to be one of the 60,000 participants selected can register for the event lottery online anytime during the eight day period beginning Saturday, March 15th until Saturday, March 22nd. **After the lottery, look for news from the APDA-GA Chapter with further information regarding our team!** Jessica Sherrill, Board Member



Tango Research

Drs. Madeleine Hackney, J. Lucas McKay, and Lena Ting of the Emory University School of Medicine are studying the effects of Tango on balance and mobility in adults over 40 with and without PD. This research study requires three 3 hour visits including balance and walking testing. You may also be asked to participate in 20 tango lessons, which will meet one and a half hours, 2 times per week for 10 -12 weeks. For information, please contact Dr. J. Lucas McKay at 404-385-2115, j.lucas.mckay@emory.edu or 1760 Haygood Drive, Suite W 200, Atlanta, GA 30322.

At this time, there are about a dozen drugs available to treat Parkinson's disease. These drugs primarily target the replacement of dopamine loss. This loss of dopamine correlates primarily with motor symptoms of the disease including slowness, stiffness and tremor. However, not all motor symptoms are dopaminergic. There are some motor features that do not respond to dopaminergic drugs including freezing of gait and poor balance with falling. Furthermore, it is well known that Parkinson's patients also experience several non-motor features and there are limited treatment choices for these. Medications that are available only provide modest benefit. Research has shown in recent years that Parkinson's disease is much more than dopamine loss. Other brain regions and neurotransmitters are impacted and it is believed that non-motor and unresponsive motor features relate to these other non-dopaminergic brain changes. Some of the notable non-motor problems that will be discussed include cognitive loss, low blood pressure and constipation.

Cognitive loss is probably the greatest unmet need in Parkinson's disease. There are several types that occur. We generally classify them into two subtypes, mild cognitive impairment (MCI) and dementia. Mild cognitive impairment is defined as cognitive change that is noticed by patient and or caregiver, but does

not (yet) impair daily function. There are several types, but most prominent are executive dysfunction or non-amnestic type and memory loss or amnestic type. Executive dysfunction is believed to relate to loss of dopamine and impacts frontal lobe function including planning, organization, set shifting, and multi-tasking. Amnestic is mostly temporal lobe and is similar to that seen in Alzheimer's disease with a primary effect on memory. Many patients have a combination of these. While these are simplified

Cognitive loss is probably the greatest unmet need in Parkinson's disease.

descriptions this represents a useful categorization. Both types are seen in Parkinson's and at this time it is unclear if either or both lead to dementia as seen in Alzheimer's disease. There are also at least three subtypes of dementia; that which comes from degeneration of cholinergic neurons in the brainstem, referred to as Parkinson's disease dementia; Lewy body dementia, which is associated with Parkinson's pathology spreading to the cerebral cortex, and Alzheimer's disease. Treatment at this time includes a

group of drugs call cholinesterase inhibitors (Aricept, Exelon, and Razadyne) and these have a modest effect on dementia, but the impact on MCI is unknown.

Low blood pressure is a serious problem in Parkinson's disease. It can be a manifestation of disease related to degeneration of the autonomic nervous system or medications or both. The autonomic nervous system function relates to loss of norepinephrine. Low blood pressure by itself can make one feel fatigued with low energy. This is a common problem in patients, as well as neck and shoulder pain. If the blood pressure drops when going from lying down to sitting or standing position, the person feels lightheaded and may pass out. This is a common cause of falls and could result in significant disability. We call this orthostatic hypotension.

Dopaminergic drugs can enhance this symptom. The problem is lowering doses leads to increased motor problems. We generally treat orthostatic hypotension first with avoiding standing up quickly, large meals, hot showers, increased fluid and salt intake and keeping the head of the bed up at 30 degrees at night and use support hose. We also remove medications that lower blood pressure. If these steps do not work, we use two unproven drugs, Florinef which works through fluid retention and Midodrine which is a vascular constrictor.

These drugs are not universally effective and more severe cases are generally non-responsive.

Constipation is defined as the passage of hard stools less than three times a week or difficulty passing stools. It is a common problem in Parkinson's disease affecting some 80% of people with PD. Many patients have this problem long before the motor symptoms begin. In fact, a history of constipation increases the risk of developing Parkinson's disease several folds. If uncontrolled, constipation can impact bladder function, medication response because of poor absorption, cause bowel obstruction and malnutrition resulting in an overall decreased quality of life. In a poll completed by the Parkinson's Disease Foundation, constipation was identified as a matter of great importance to patients because it significantly impacts daily living. Treatment is currently limited to behavioral treatments such as adequate fluid intake - six 8 oz. glasses of fluid per day, increased dietary fiber, exercise and regular bowel habits. One study indicated that Polyethylene glycol is safe and effective. One small short term trial suggested that Amitiza may be helpful. Other agents including stool softeners, fiber supplements and magnesium-based products are recommended, but with little evidence.

All three of these problems are in need of better understanding and

therapies. Recently multicenter, randomized controlled trials have begun to examine agents that might improve outcomes for all three. For cognition, a monoamine oxidase inhibitor is being examined. This drug could potentially increase brain norepinephrine, serotonin and dopamine and hence may have a positive effect on memory, including slowing down the disease process. For orthostatic hypotension, a noradrenergic drug is being studied. Preliminary data supports its effectiveness but further data is needed. Finally for constipation, a drug that mimics the effect of a hormone called Ghrelin is being studied. Ghrelin is a natural occurring protein that increase bowel motility and thus can improve constipation. Each treatment represents a novel approach.

Emory is an investigative site for each of these studies. We are looking for volunteers to participate. The studies have specific inclusion and exclusion criteria which limits, to some extent, who can and cannot participate. That means some interested subjects may not be able to join the study, which we understand is frustrating. That also means we need many more volunteers to just enroll a few people. Getting new drugs approved is a long and arduous process. It is discouraging to patients and physicians who eagerly await advances and new options. Two keys to getting new drugs to market are having knowledgeable

and motivated investigators to do the studies correctly. In addition, it is important to have interested and educated volunteers. No subjects, means no advances in disease. So we are asking you to volunteer. We try very hard to accommodate subjects' wishes about times of appointments. We understand the traffic problems and we try to make this as pleasant a process as possible. Let's work together to make strides in treating these and other non-motor/non-dopaminergic features of Parkinson's disease.

GET INVOLVED

Moderato Study

Eligibility:

- Men/Women between 45-80 with PD
- On Levodopa or dopamine agonist for 30+ days before the start of study

Call Elaine Sperin, LPN

404-728-4786

Medication Study for Low Blood Pressure

Eligibility:

- Men/Women over 18
- Ambulatory
- Clinical diagnosis of symptomatic orthostatic hypotension

Call Mary Louise Weeks, RN

404-728-4982

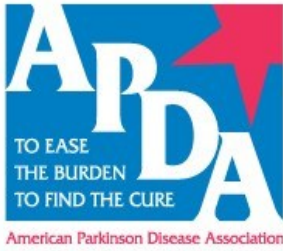
MOVE-PD Study

Eligibility:

- Men/Women over 18, with PD
- Chronic constipation for past 3 months
- Good general health

Call Mary Louise Weeks, RN

404-728-4982



The 2014 Liberty Mutual Invitational Golf Tournament

benefiting APDA Georgia Chapter

Monday April 28, 2014 Smoke Rise Country Club

in Stone Mountain



The American Parkinson Disease Association Georgia Chapter is hosting an exciting fund raising event and we need your support. Your sponsorship dollars will make a direct and meaningful impact on the lives of those affected by Parkinson's Disease right here in Georgia.

The American Parkinson Disease Association (APDA) was founded in 1961 to facilitate patient and family support, medical research, and education. APDA Georgia carries out that mission through support of respite programs for caregivers and various exercise programs. The APDA Information & Referral Center provides education, counseling, assistance and referrals for the Parkinson's community.

Monday April 28, 2014, 8:30 am Registration, 10 am Shotgun Start - Smoke Rise Country Club

Enjoy a round of golf at the recently renovated Smoke Rise Country Club and support Parkinson's disease research, public awareness and Caregiver Respite programs! Each player will receive a player's gift bag, on course lunch and an Awards Dinner at the clubhouse. Prizes awarded to 1st and 2nd Place teams. Contests include Closest to the Pin, Longest Drive, and Hole-in-One prize. Don't forget the exciting Putting Contest! All winners will be announced at the Awards Dinner Immediately following play.

For sponsorship information or if you would like to play in the event

please go to www.apdageorgia.org or contact Barbara Mooney at 404-325-2020

APDA Georgia Chapter, PO Box 49416, Atlanta, GA 30359

Community Conversations with Emory PD Researchers

Since our Emory-Udall Advance PD Research Center Roundtable event began in 2010, attendance has grown steadily and this year should be no different. Our "Community Conversations with Emory PD Researchers" will be held on Saturday, May 17, 2014 from 10:00 am – 1:30 pm at the Claudia Nance Rollins School of Public Health, 1518 Clifton Road, Atlanta, GA 30322.

The format is quite different from our monthly Education meetings at Clairmont Oaks. At this event, we will have 15 PD researchers making the rounds to small groups to discuss their latest research. Each presentation will be 30 minutes in length and will cover a range of topics from "Biomarkers & Early Detection", "Sleep Disorders in PD", and "Cognitive Impairment and Dementia in PD to name a few. Attendees will have an opportunity to hear three topics and ask questions from the scientists conducting the various studies and trials.

After the presentations, lunch will be served and this year our keynote speaker will be Mahlon Delong, M.D., Professor of Neurology at Emory University and one of the recipients of the 2014 Breakthrough Prize in Life Sciences. Dr. Delong was recognized as a breakthrough pioneer in defining the interlocking circuits in the brain that malfunction in Parkinson's disease, laying the groundwork for treatment of the disease with deep-brain stimulation. The event is free, but you must register to attend. Registration will begin March 10th.

Go to www.udall.emory.edu/communityoutreach/index.html for more information.

Donations made to the APDA Georgia Chapter

Donations:

Barbara Aiken	Thomas & Margarita Patterson
John and Marilyn Allen	Bryan Payne
Joyce & Floyd Anderson	Bill & Faye Pender
Mary Apps	Alden & Carol Pendery
Belmont Village Johns Creek	Frank & Eileen Piasecki
Amy Bowers	Donald Prichard
David & Diane Braun	Iris Regas
Mr. & Mrs. John. M Buice	Clarke and Maria Rodgers
Christopher Burds	Jim & Judy Shaw
Tiia Carswell	Jessica Sherrill
Dave and Carol Colwell	Thomas and Dianne Sherrill
Bob & Faye Crawford	Sunrise Senior Living at Buckhead
Dr. Paul Cronce	John and Susan Taylor
Mr. & Mrs. Terry & Judy Cullifer	Karen Thompson
Jessica De Souza	Kathleen Tucker
Douglasville Support Group	Vaughn W. Brown Charitable Trust
Lois Effler	Allan & Joan Walker
Alick & Jean Elliott	Kristy Weathers
Robert & Jean Ennis	Jim & Theresa Weeks
William Frazier	Jerry Zickafoose
Marvin & Fran Galarza	ZogSports ATL
Sarah Gay	
Marshall & Susan Gerstel	Miriam Amerson Bell
David Glover	Lee and Laura Oakley
Wayne and Georgia Gross	Cary Booker
Johnson and Annette Hall	Herbert and Martha Blondheim
Paula Hill	Betty Jane Martin Coker
HomeWell Senior Care	Alba Horacio
Chuang Hsu	Dr. Don William DeBra, Jr.
Wayne & Patsy Huey	Joseph and Phyllis Arnold, MD
Huntcliff Summit Senior Living	George and Gayle Hynds
Robert and Barbara Hunter	Norman Jacobs
Miles P. Hurley	Clyde and Jacqueline Mynatt, Jr.
Robert & Ann Inman	Wilbur and Ruth Newman
David Jones	Amy Robinson
Kadan Homecare	Colonel Irving and Mrs. Ann Schoenberg
Hedwig Kaiser-Pollio	Dr. Stuart and Mrs. Alida Silverman
Harold & Mildred Kello, Sr	Bert Skellie
Kimberly Clark Foundation	Martha Ann Dodd
Fred Kimble	Behavioral institute of Atlanta
Grace Loadman	Jack and Celeta Cavender
Dan & Kirsten Magee	Judith Clarkson
Karen Maloney	Reese Currie
Joseph Mayson	Thomas and Doris Fearington
Brenda Mazzocchi	James and Anne Meadows
Jim & Dixie McKelvey	Harriet Nall
Jimmy & Vivian McMullan	Bill and Eugenie Schuh
Daniel & Diane Melnick	Wayne Fulmer
Doris Nichols	Edward and Gwen Farmer
Paul and Jacqueline Odom	Fielden A. "Bud" Jackson
J. H. & Sue Passman	John and Barbara Trulock

In memory of:

John and Barbara Trulock

Jean Knapp

Dorothy Spitzer

Dr. Price Lineberger

Julian Mohr

John C. "Jack" McCune

Jane C Von Seggern

Robert Yellowlees

Dr. William D. McKillip

Joan Berryman

Robert Christian

Dr. Thomas and Sara Cooney

Mary Kay Corbitt

Thomas Fitz, Jr

Beth Greeson

Kellie and Freddy Jones

Jeremy and Carlene Kilpatrick

David and Mary McKillip

National Supply Co.

Denise Spangler

George and Irene Diamond Stanic

James and Corene Wilson

Michael Wiser

John A. Plageman, Jr.

L T and Mary Allison

Chattanooga Skin & Cancer Clinic

Mr. and Mrs. Kevin Ofchus

Marjorie Yates

Paul Price

Kelly and Jean Price

George D. Queener

Payne Midyette, Jr.

Alex & Shirley Millican

John Montgomery, Jr.

Potts **Brothers** Land and Auction

Rick Sauer

Royal Yates

Maryann Somers

Lin Barker

Terri Couch

Mark and Jackie Hagan, Jr.

Nancy Owings

Beverlyann Rupinski

Edward Somers

Synnex Corporation

Frank D. White

Harry Burnette

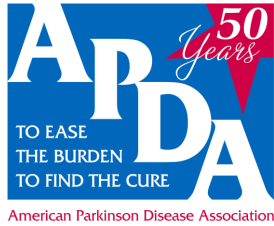
Sylvia L. Willis

John & Dove Johnson

Honors:

Evelyn Beatrice Doster	Amanda Schertz
Frankie Baughn	Diane Schulman
Dr. Julian Duttera	Robby Schultz
John & Diana Coleman	Kevin Sergeant
Morris Handman	Mark & Kathryn Sheerin
Larry Handman	Thomas & Dianne Sherrill
Thomas Hanner	Alison Sherrill
Wayne & Helen Bundrick	T Donnell & Charlotte Smith
Kimberly Rodriguez	Carol Spurlock
Steve & Renee Haas	Michelle Taliaferro
Lynn Ross	Ann Teh
Larry & Ellie Kahn	Kathleen Tucker
Joyce Sanders	Bill Wakefield
Charles and Carol Gearing	Linda Gwynn Walton
Jessica Sherrill	Sarah Watchko
Valerie Alino	Ashley Whitlock
Ken Ambellan	Barbara Wiley
Nuno Azeredo	Bill & Sara Wilkins
Katrina Barrett	Becky Williams
Susan Bertucci	Robert Windholtz, Atty
Krista Brooks	Jenny Wolfe
Susan Bryant	Lynn Wyatt
Eric Burkard, CLTC	David Zaksheske
Kristen Comer	
Aline Cook	
Michael Copenhaver	
Barry and Shirley Daniel	
Sally Darby	
Josh Gerber	
Alan Goodman	
Kristin Gresham	
Chris Griffiths	
Kami Henson	
Candice Houser	
William Hungeling	
Pam Hutchins	
Harman Jenkins	
Richard Leeds	
Kimberly Lerman	
Anne Lerner	
Monica Luck	
Emily Lunz	
Adrienne Mondragon	
Theodore Noble	
Kimberly Odum	
Mr. and Mrs. Stuart Phillips	
Juleah Pierzchala	
Amanda Pierzchala	
Xavier Puplett	
Michelle Ramos	
Laurel Riehle	

Gifts can be given by mail, phone, or on-line:
 Georgia Chapter APDA
 P. O. Box 49416
 Atlanta, GA 30359
Phone: (404) 325-2020
www.apdageorgia.org



American Parkinson Disease Association
Information & Referral Center
1841 Clifton Road
Atlanta, GA 30329

MARK YOUR CALENDAR!

Educational Meetings are held at Clairmont Oaks
441 Clairmont Avenue, Decatur, GA 30030

March 15, 2014	Camille Vaughan, M.D.	"Bladder Matters"
April 19, 2014	Cindy McCall, RN	"Hospice 101"
May 17, 2014	"Community Conversations with Emory PD Researchers"	
August 16, 2014	Jorge Juncos, M.D.	"PD Update 2014-2015"

No Meetings in June or July