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. “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.
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
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 Georgia Chapter Gives Back

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.lucus.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 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 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

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**Gifts can be given by mail, phone, or on-line:**

- Georgia Chapter APDA
- Atlanta, GA 30359
- Phone: (404) 325-8900

**www.apdageorgia.org**
MARK YOUR CALENDAR!

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

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<td>May 17, 2014</td>
<td>“Community Conversations with Emory PD Researchers”</td>
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No Meetings in June or July

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 patients’ physician.