

Parkinson's & Us



A Publication of APDA I&R Center and the Georgia Chapter

Summer 2016

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A Comprehensive Model of Care for PD

It has been demonstrated that non-motor symptoms such as cognitive, psychiatric, sleep, bowel, bladder and blood pressure symptoms, are more closely correlated with quality of life in Parkinson's disease (PD) than classical motor features of tremor, rigidity, slowness and walking issues. Furthermore, worse Quality of Life (QOL) is associated with significant caregiver strain and is associated with more frequent hospitalizations. Quality measures and guidelines for therapy emphasizing non-motor features have been published and validated questionnaires developed to monitor and increase awareness of these problems. Nevertheless, non-motor features are still frequently unrecognized and under-diagnosed, appropriate evaluations are not completed, and treatment is not initiated.

With the realization that PD is associated with multiple non-motor symptoms and medical comorbidities, it became clear that PD is not just a movement disorder but instead requires interdisciplinary care. The current mode of clinical care delivery by subspecialties, however, results in unbalanced, fragmented, inconvenient and, often, less than optimal care. This could be part of the explanation behind under-recognition and failure to treat the aforementioned non-motor features. That the current healthcare system does not deal comprehensively with the range of problems afflicting persons with chronic neurological disease is well known and creates an unnecessary burden of time, money, and exacerbated physical and emotional health problems. Optimal care for PD should be provided at a single site that brings together the necessary disciplines. Hence, a major goal of the Emory Movement Disorder Program was to develop a patient-centered comprehensive care program that brings interdisciplinary care to the patient under one roof. We believed this would improve clinical outcomes in patient care and QOL by making care more patient-friendly, coordinated, and timely.

At Emory, we found ourselves in an ideal situation to develop such a program as the key departments (geriatric medicine, rehabilitation medicine, psychiatry, sleep medicine, neurology, and neuropsychology) were located geographically close. The program was initiated with the help of Dan and Merrie Boone. Due to Merrie's diagnosis of Parkinson's disease, they had traveled to several centers in the U.S. and were well versed on what types of programs existed. With the generous philanthropic gift from them, in April 2010, the Comprehensive Care Clinic (CCC) was initiated. The CCC involves a two-day visit to the Emory Brain Health Center which gives the patient and caregiver the opportunity to meet with the following departments. On Day 1, they are evaluated by sleep medicine, psychiatry, geriatric medicine, speech and language therapy, occupational therapy, and social services. On Day 2, patients have neuropsychological testing, an evaluation by a physical therapist, and the visit is summarized by a movement disorder specialist. If needed, sleep studies, laboratory, and MRI evaluations are arranged. All potential patient referrals come through the program nurse coordinator. Once diagnosis is confirmed by medical record review, the appointment date is set. An email goes out to the CCC team and each department schedules the patient and retains insurance approval. **Con't page 6.**

A copy of the care plan is sent to the patient and caregiver, the referring physician and primary care physician. The team of the CCC meets regularly to discuss each patient. The nurse coordinator follows-up with the patient and family after the meeting to facilitate

President's Corner



Happy Summer to Everyone!

We hope you enjoy this newsletter and find something helpful, whether it's Dr. Stewart Factor's article on Emory's Comprehensive Care Clinic, our monthly Saturday education meetings, a support group activity, a particular service or even a fundraising event.

At the Georgia Chapter we have been working diligently to secure and grow funding for the various programs and services we support such as Education and Awareness, Exercise, Care-giver Respite and others. I'm pleased to say the results from these programs has been successful across the board.

We look forward to seeing everyone at our free education meeting and breakfast the third Saturday of every month (next one will be Saturday, August 20, 2016) and also at our formal Gala fundraiser on Saturday, November 5, 2016 in Buckhead, so please mark your calendars! More details on the Gala will follow, but it will be an evening of great fun, music, food, friendship, prizes and unique silent auction items, and all for a great cause!

Finally, we wish to recognize our many supporters over the past year, without whose contributions our dual mission would not be possible. Thank you again for helping us "*Ease the Burden - Find the Cure*".

We look forward to seeing you soon!

Warmest regards,

Eric

Eric Burkard
President
APDA Georgia Chapter



American Parkinson's **OPTIMISM** **Runs for Georgia**

APDA Runs with Optimism at the 2016 Peachtree Road Race

Thank you to our fundraisers!

Eric Burkard
PD Gladiators:
Larry and Ellie Kahn
Gil and Gina Kim
Rick Tuley
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And a special **THANK YOU** to their many supporters:



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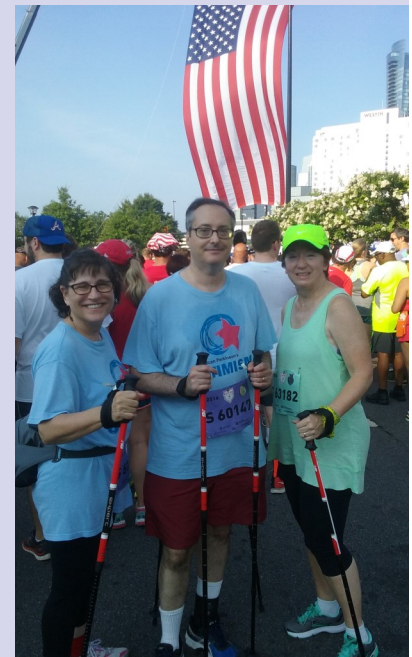
Above: Ellie and Larry Kahn

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with Gina Kim

University of Pittsburgh Researchers Find Key to Parkinson's Disease Neurodegeneration—Press Release June 2016

The American Parkinson Disease Association helps fund research that could lead to new therapies to slow or stop progression of Parkinson's disease.

New York, NY, June 8, 2016 – The American Parkinson Disease Association is a funding partner in supporting researchers at the University of Pittsburgh School of Medicine who have uncovered a major reason why the Parkinson's-related protein alpha-synuclein, a major constituent of the Lewy bodies that are the pathological hallmark of Parkinson's disease, is toxic to neurons in the brain. The finding has the potential to lead to new therapies that could slow or stop progression of the devastating illness. The new research appears online today in *Science Translational Medicine*.



J. Timothy Greenamyre, MD, PhD, Love Family Professor and Vice Chair of Neurology University of Pittsburgh Medical Center

According to David G. Standaert, M.D., Ph.D., Chair of the APDA Scientific Advisory Board, John N. Whitaker Professor and Chair of Neurology, and Director of the Division of Movement Disorders at the University of Alabama at Birmingham, "This is a very important study. It provides new insight into two of the critical mechanisms in Parkinson disease: aggregation of the protein alpha-synuclein and dysfunction of mitochondria, the 'powerhouse' of neurons. It opens doors to new kinds of treatments to slow or prevent the disease."

The University of Pittsburgh School of Medicine is one of eight APDA Centers of Advanced Research. Lead investigator J. Timothy Greenamyre, M.D., Ph.D., Love Family Professor of Neurology in Pitt's School of Medicine and director of the Pittsburgh Institute for Neurodegenerative Diseases (PIND) is also the director of the APDA Advanced Center for Parkinson's Disease Research at PIND and a member of the APDA Scientific Advisory Board. "It's really exciting that we have found a mechanism we can target to create new treatments for this devastating disease," said Dr. Greenamyre. "I've been involved in Parkinson's research for more than 25 years and the further I go along, the more urgency I feel to translate what we're doing in the laboratory into something that's going to make a meaningful difference for people affected by

Parkinson's disease. I believe these findings will have a lot of impact in the Parkinson's research community. We couldn't have done it without the support of APDA!"

Parkinson's disease (PD) is a degenerative neurological disease characterized by tremor, slowness, and gait and balance difficulties that affects about 1 million people in the United States. The symptoms are caused by the degeneration and loss of neurons in the brain, particularly those crucial for the initiation and coordination of movement.

PIND's goal is an integrated, interdisciplinary approach to the study of neurodegenerative diseases and their mechanisms, with the aim of transforming cutting-edge science into novel therapies and diagnostics that directly benefit individuals affected by neurodegenerative diseases.

What researchers do know is that the degenerating neurons contain large clumps of a protein called alpha-synuclein. Researchers found that people whose cells make too much alpha-synuclein, or make a mutated form of the protein, are at high risk of developing PD because of the protein's toxicity. Scientists also demonstrated that the accumulation of alpha-synuclein in PD is toxic because it disrupts the normal functioning of mitochondria.

In the new study, Dr. Greenamyre and his team – led by coauthors Roberto Di Maio, Ph.D., and Paul Barrett, Ph.D., both of PIND – used a well-established rodent model of PD to show exactly how alpha-synuclein disrupts mitochondrial function. They found that by attaching to a mitochondrial protein called TOM20, alpha-synuclein prevented the mitochondria from functioning optimally, which resulted in the production of less energy and more damaging cellular waste.

"Ultimately, this interaction between alpha-synuclein and TOM20 leads to neurodegeneration,"

The researchers then confirmed their animal findings in brain tissue from people with PD.

"The effects of alpha-synuclein on mitochondria are like making a perfectly good coal-fueled power plant extremely inefficient, so it not only fails to make enough electricity, but also creates too much toxic pollution," said Dr. Greenamyre.

Using cell cultures, the research team also found two ways to prevent the toxicity caused by alpha-synuclein – gene therapy that forced the neurons to make more TOM20 protein protected them from the alpha-synuclein, and

a protein that was able to prevent alpha-synuclein from sticking to TOM20 prevented alpha-synuclein's harmful effects on mitochondria.

While more research is needed to determine whether these approaches could help PD patients, Dr. Greenamyre is optimistic that one or both may ultimately make it into human clinical trials in an effort to slow or halt the otherwise inevitable progression of PD.

Coauthors of the study are Charleen Chu, M.D., Ph.D., Edward Burton, M.D., Ph.D., Teresa Hastings, Ph.D., Eric Hoffman, Ph.D., Caitlyn Barrett, Ph.D., Alevtina Zharikov, Ph.D., Anupom Borah, Ph.D., Xiaoping Hu, B.S., and Jennifer McCoy, B.S., all of PIND.

APDA is proud to have been one of the funders of this collaborative effort. Additional research grants were awarded from the DSF Charitable Foundation, the Ri.MED Foundation, the Consolidated Anti-Aging Foundation, the National Institutes of Health (grants NS095387, NS059806, ES022644, ES020718, ES020327, NS065789, AG026389 and P50AG005133), the United States Department of Veterans' Affairs (grant 1I01BX000548), the Blechman Foundation, and the Department of Biotechnology, Government of India.

About the University of Pittsburgh School of Medicine

As one of the nation's leading academic centers for biomedical research, the University of Pittsburgh School of Medicine integrates advanced technology with basic science across a broad range of disciplines in a continuous quest to harness the power of new knowledge and improve the human condition. Driven mainly by the School of Medicine and its affiliates, Pitt has ranked among the top 10 recipients of funding from the National Institutes of Health since 1998. In rankings recently released by the National Science Foundation, Pitt ranked fifth among all American universities in total federal science and engineering research and development support.

APDA Parkinson's Disease Spotlight Webinar Series

This special series is offered to allow people with Parkinson's, care partners, families and medical professionals to gain insight into the treatment and management of Parkinson's symptoms and quality of life. Visit www.apdaparkinson.org/webinar to view the archived series.

LSVT BIG® Homework Helper

Many in the Parkinson's community are familiar with the Lee Silverman Voice Therapy, LOUD® and the BIG physical therapy program developed especially for people living with Parkinson's disease. (PD). These are evidence-based treatment approaches for individuals with PD and other neurological disorders. The BIG program is taught by LSVT certified physical or occupational therapists, usually in an outpatient setting. Recently, they have introduced the BIG Homework Helper – DVD, a limb and body movement exercise program designed for people with PD. It was created for people to use as an adjunct to the BIG® treatment delivered by an LSVT Certified Clinician. It can also be used:

Prior to treatment as an introduction to the therapy

During treatment as a guide for homework exercises

After treatment as a motivation to practice and keep moving

The DVD is NOT physical or occupational therapy and it should only be used with approval of each person's PT or OT and physician. For more information and to order, go to www.lsvtglobal.com/products.

Did You Know?

The 4th World Parkinson Congress will meet September 20—23, 2016 in Portland, Oregon. This year's meeting will be held in the Oregon Convention Center in downtown Portland. The triennial World Parkinson Congresses provide an international forum for dialogue on the latest scientific discoveries, medical practices, and caregiver initiatives related to Parkinson's disease. Each Congress brings together physicians, neuroscientists, a broad range of other health professionals, care partners, and people with PD (PwPs) for a unique and inspiring experience. Cross pollinating members of the community is important in the effort to expedite the discovery of a cure and cultivate best treatment practices for this devastating disease. For more information, go to www.worldpdcoalition.org.

Con't from Page 1

During the final day visit with the movement disorder neurologist, a comprehensive care plan is created based upon patient and family goals and priorities for care. A copy of the care plan is sent to the patient and caregiver, the referring physician and primary care physician. The team of the CCC meets regularly to discuss each patient. The nurse coordinator follows-up with the patient and family after the meeting to facilitate follow-up as needed and assess the implementation of the plan.

Since execution of the comprehensive care program, more than 200 patients have been evaluated. The outcome of this experience has been significant with an improvement of quality of life and response from the patients that this approach addresses issues that matter to the patients and caregivers. Patient satisfaction is high. This strategy has proven to be preventative (for such problems as falls), therapeutic (for non-motor and motor issues) and diagnostic (differentiating PD from atypical Parkinsonism and for non-motor features).

As it relates to quality of life, treatment in the PD CCC model has been associated with notable improvement. After 6 months, improvement in QOL related to independence in activities of daily living (ADLs) and mobility has been noted. For example, an evaluation of the first 95 persons to participate in the PD CCC, showed that non-motor features are very common; 79% were diagnosed with a psychiatric condition, 76% with mild cognitive impairment or dementia, 98% with a sleep disorder or symptom, and 95% had evidence of clinically significant autonomic dysfunction. Additionally, 86% received recommendations for rehabilitation therapy. Data from the PD CCC demonstrate consistent identification of non-motor symptoms in addition to initiation of treatment plans to address motor and non-motor symptoms. The dimension scores for mobility and independence in activities of daily living (ADL) were particularly improved. These data demonstrate promising evidence that coordinated, comprehensive care through the PD CCC model leads to clinically significant improved PD QOL up to 6 months after evaluation. We will continue to work on such a model with the goal of an overall change in the model of care for PD and perhaps a new model for reimbursement and improved access to such programs. There may also be an opportunity to expand this model further through telemedicine. If you would like more information regarding the Merrie Boone Comprehensive Care Clinic for PD, please contact Tammyjo Best, LPN, CCC program Coordinator at 404-712-6990. By Stewart Factor, D.O.



Emory Rehab Moves to Executive Park



Big changes are happening at the Emory Brain Health Center. The Emory Rehabilitation Hospital Comprehensive Outpatient Clinic is open at 12 Executive Park. The clinic, located on the 4th floor, will provide Physical, Occupational, and Speech therapy services to people living with neurological disorder. The clinic is equipped with state-of-the-art equipment and will provide excellent outpatient care.

Of particular interest to people living with Parkinson's disease, (PD), the Lee Silverman LOUD and BIG therapies will be available in the same building with the Emory Movement Disorders Program. The Lee Silverman Voice Treatment (LSVT) for PD was developed over 20 years ago at the University of Arizona. Based on research methods for speech improvement, many PD patients have benefitted and it is now implemented worldwide. Later a course of physical or occupational therapy, BIG, was developed. This program focuses on training individuals with PD to use bigger movements to improve their balance, enhance faster walking and allow more ability to turn their trunk.

A clinician must be LSVT certified to provide either therapy and a physician's prescription is required. Medicare insurance covers both treatments at their usual 80% and some insurance companies will cover the remaining 20%. At this time, the Clinic is unable to accept Medicaid. If 12 Executive Park is convenient, at your next appointment with your neurologist, ask if he/she recommends either or both therapies for you. Physician referrals can be faxed to 404-712-5974. The Clinic hours are Monday—Friday 7:30 am—5:00 pm.

In Loving Memory

James Akridge
Dunwoody Highlands Club

Herbert Berch
Marcia Rosenberg

William Clement
Annette Payton

Mary D'Antonio

Beatrice Liberato
Linda Farley
Frances Colona

Paul Doster

Ellis & Ellis Investment Management
John Murphy

Kenneth Easter

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Wendy Murphy

Robert Fleming

Mike & Laurie Boyd
Tom and Helen Boyd

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William Mays

Nancy and Lee Proctor

Robert and Joan Snyder

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Joan Teuscher

Kathleen Bohan
Jennifer Brasfield
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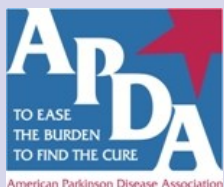
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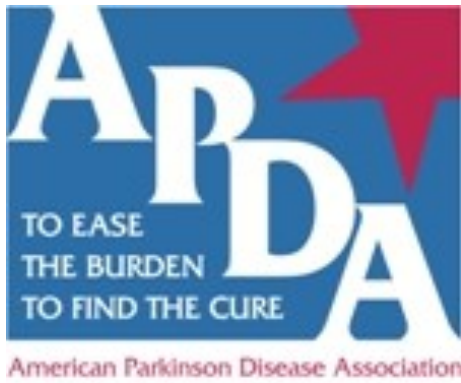
Mary Amerson Burt
Lee & Laura Oakley

Donations and Memorials may be made online: www.apdageorgia.org or by mail.

The American Parkinson Disease Association Georgia Chapter

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Educational Resources

The APDA Georgia Chapter's website www.apdageorgia.org is the source of many free educational and patient/caregiver support materials. A complete list of booklets, supplements and other publications are also available. Most can be downloaded. Also available is a complete list of Support Groups and Exercise Programs as well as resources supported by APDA nationally as listed below:

APDA Information & Referral Centers are the regional patient/caregiver resources for education materials, physician and social services referrals, support groups and programs. A network list by site is available on the website

APDA's National Young Onset Center — www.youngparkinsons.org, 888-223-3801, apda@youngparkinsons.org, addresses the unique challenges to young people with PD and their families

APDA's National Resource Center for Rehabilitation — 888-606-1688, rehab@bu.edu, provides direct access to a licensed physical therapist for questions about exercise, information about programs in the caller's area and educational materials.

APDA's National Veterans Center— 888-838-6265 ext. 1715, susan.gulas@va.gov, assists active and retired members of the U.S. armed forces with PD and their families.

MARK YOUR CALENDAR!

The monthly Education Meetings are held at Clairmont Oaks
441 Clairemont Avenue, Decatur, GA 30030
10:30 a.m. beginning August 20, 2016

The APDA Georgia Chapter Gala
Saturday, November 5, 2016
A night of fun and excitement!

Join our mailing list at www.apdageorgia.org for this and all of the latest news and events!