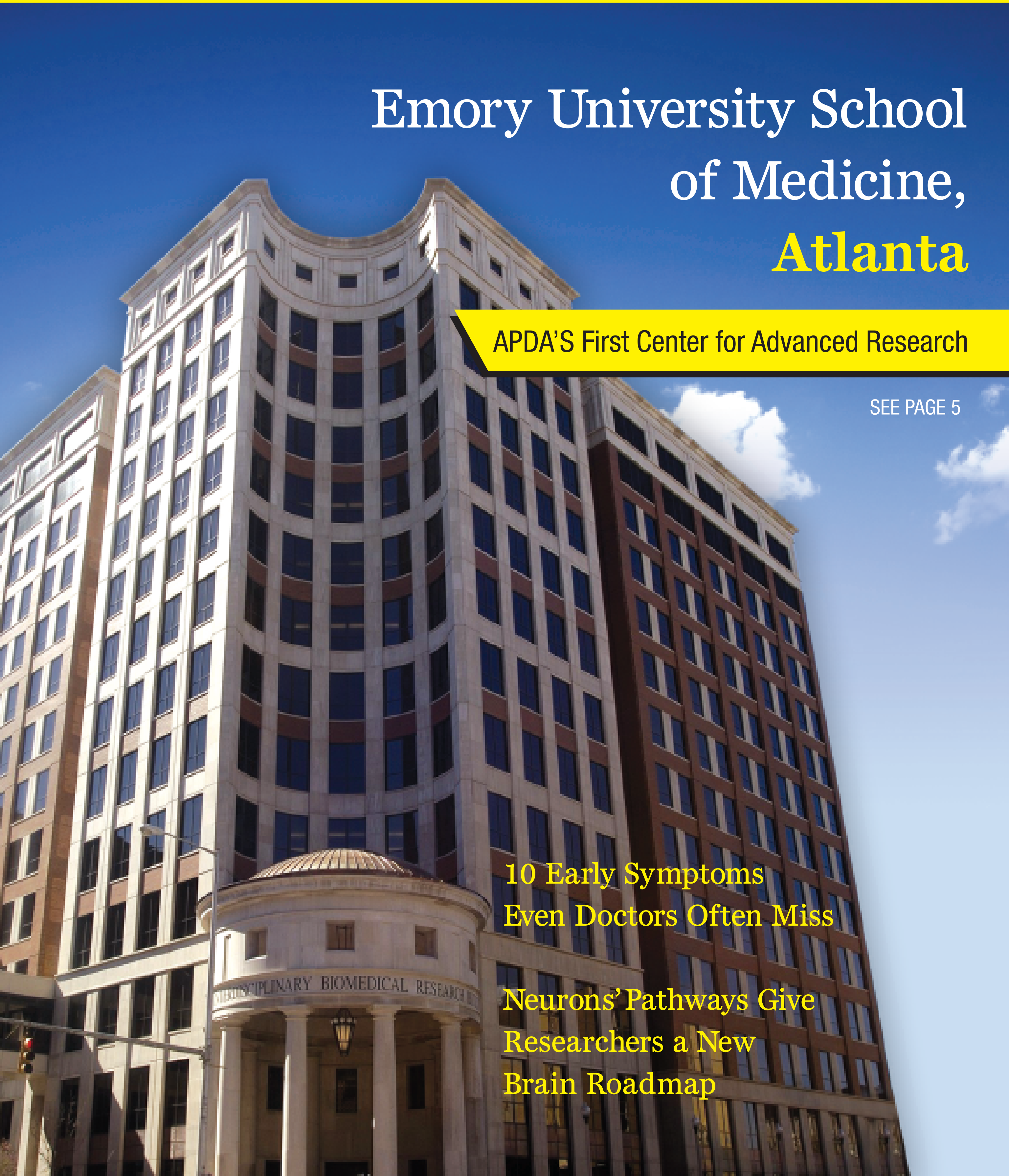
APDA
TO EASE
THE BURDEN
TO FIND THE CURE

AMERICAN PARKINSON
DISEASE ASSOCIATION

SUMMER
2012 ISSUE



Emory University School of Medicine, Atlanta

APDA'S First Center for Advanced Research

SEE PAGE 5

10 Early Symptoms Even Doctors Often Miss

Neurons' Pathways Give Researchers a New Brain Roadmap

FROM THE CHAIRMAN

Joel A. Miele Sr., PE

Reading a recent article in a philanthropy publication brought me good news.

According to its research, donors support charities because of what they have accomplished, not because of the organization's needs caused by a poor economy or other external factors. Also good to hear is that increasingly donors are reaching out to a charity, with more than half turning to the organization's website to learn what it has done and plans to do.

That is good news indeed, and I encourage all to visit our newly upgraded website, www.apdaparkinson.org. The number and variety of free resources that APDA provides still impress me when I see them enumerated on the screen. Our services include: national centers dedicated to young onset and veterans; professionals' responses to general medical questions and physical therapy and exercise guidance; an online caregivers' coordination service, and a library of free literature written by foremost experts in their fields. APDA provides them all, and has increased rather than reduced its services during the past challenging years, while supporting nine centers for advanced research in prestigious academic and medical institutions.

Our own major good news is that Leslie A. Chambers, former Easter Seals Coastal Fairfield County Executive Director of Advancement, has been named APDA's new president & CEO. Ms. Chambers brings a strong track

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IN THIS ISSUE

FROM THE PRESIDENT & CEO

Leslie Chambers

As I prepare for my new role with APDA, I am delighted by the warm welcome I have received from many of you throughout the country. Leadership transitions are an exciting time, and I am so pleased by the sense of optimism and vision of the future as it relates to the outlook for the Parkinson's community.

Although as an organization, APDA has many challenges ahead, I believe that the passion and commitment toward building a better future for Parkinson's families will continue to drive us toward success. Building on our past accomplishments and achievements through our support of research and local community support, I look forward to the continued input and feedback from folks around the country as we shape our future together. Building this future will require collaboration from all sectors of our organization including volunteers, staff, board of directors, researchers, patients, donors, community and national healthcare leaders, and all who are willing to "ease the burden and find the cure."

I look forward to this new leadership opportunity with great anticipation and enthusiasm and thank you for your ongoing support of our mission at APDA.

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135 Parkinson Ave.
Staten Island, N.Y. 10305
800-223-2732
apda@apdaparkinson.org
www.apdaparkinson.org

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ASK THE DOCTOR

By Joseph Friedman, M.D.

Q: I have a habit of pill rolling, which seems voluntary because I stop when I become aware of it. Is this a symptom of Parkinson's disease?

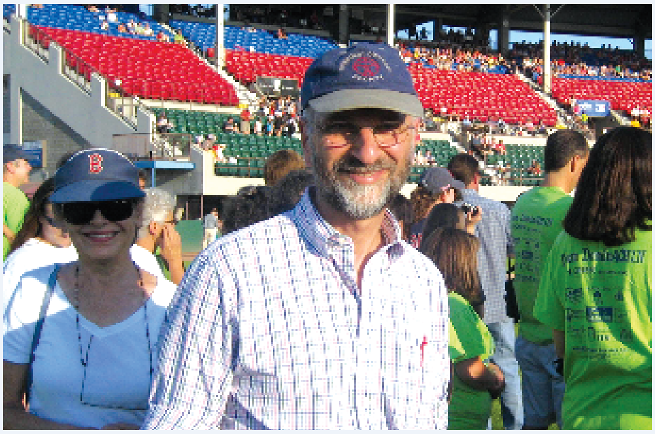
A: Parkinson's disease is diagnosed based on the presence of more than one neurological finding upon examination. A habit is something that can be controlled to some degree, whereas the tremor of PD cannot, although there are tricks that can be used to suppress it. Your habit does not sound at all like PD.

Q: What is end-dose failure? Is it part of the on/off effect?

A: End-of-dose failure refers to "wearing off," when your medicine's effect winds down as the amount of drug in your brain runs low. This is seen with L-Dopa, which does not last very long in the bloodstream. The clinical effect of L-Dopa lasts far longer than the drug does in the blood, presumably because it is stored in the brain cells which will use it by converting it to dopamine. There is no universally accepted definition for "on/off." We usually use it to mean sudden changes in clinical response to PD medications. Patients will often describe "turning off" as being like having a light switch turned off, and similarly for turning on. Most PD patients will have a gradual decline as their medication loses effect. "On/off" usually develops after many years of L-Dopa use and is rarely an early problem. It does not develop in most patients.

Q: Is there a correlation between migraine headaches and young onset Parkinson's? I have a family history of migraines, but am the only one with PD. My sister, however, has MS.

A: I am unaware of any association between migraines or other forms of headache and PD. Nor is there an association with MS. Migraines are very common in the general population so that we'd expect a lot of PD patients to have a history of migraines.



Dr. Friedman supports APDA at the field as well as in the office. Here he is among the more than 300 people at the June 28th "Night at the PAW SOX Game" in Pawtucket, R.I. The event was organized by Mike Achin, a champion in PD awareness and fundraising, to benefit APDA's Rhode Island and Massachusetts chapters.

Q: Is foot pain associated with Parkinson's at all? Not cramping.

A: PD patients suffer a lot more pain than people their age who do not have PD. The pain comes in all varieties, but usually is related to back and neck pain from the flexed posture. It also arises from the stiff shoulders and hips. Many PD patients also suffer from other pains that are much harder to explain.

Foot pain is common in the general population, especially older women who wore "stylish" shoes that maim the foot, causing bunions, calluses and toe deformities. PD patients may develop dystonia, which is an abnormal, involuntary posture that may cause toes to curl up or down, and thereby cause pain from rubbing against the shoe, or pain from abnormal positioning of the foot when walking to avoid injuring the toes. In addition to these issues, PD alters the biomechanics of walking so that minor bone and joint abnormalities may be amplified into major ones because of the changes in how weight is distributed.

Dr. Friedman is a clinical professor at Brown University School of Medicine and medical director of APDA'S Rhode Island Information and Referral Center.

MISSING EARLY AND SUBTLE SIGNS OF PD CAN PREVENT SLOWING DISEASE PROGRESSION

By Michael Rezak, MD

1. Loss of sense of smell (often accompanied by loss of sense of taste).

2. Trouble sleeping - Up to 40 percent of people who "act out" in their sleep develop PD.

3. Constipation and other elimination problems - The smooth muscles that control the bowels and bladder can become less sensitive and efficient.

4. Loss of facial expression - A slowness in smiling or frowning precedes the "Parkinson's mask."

5. Persistent neck pain - More common in women, PD-related neck pain may feel more like a tingling or numbness and does not recede like pain from a cramp or injury.

6. Slow, cramped handwriting – A manifestation of bradykinesia (loss of spontaneous movement and general slowing down). This is usually noticed by family members, who are having trouble reading the smaller, tighter, spidery writing.

7. Voice and speech changes – Slower, softer, slurred words occur as facial muscles stiffen.

8. Lack of arm swing – Subtle stiffness reduces the range of motion. It may first be noticed that one arm doesn't swing as the other does when walking, or reaching for objects becomes more difficult.

9. Excessive sweating – The autonomic nervous system regulates the body, and when PD affects the way it operates, there are changes in the skin and sweat glands.

10. Changes in mood and personality – Reduced ability to multitask is a common first sign of "executive functions" decline. Anxiety and withdrawal from new and social situations are often overlooked as a disease symptom.

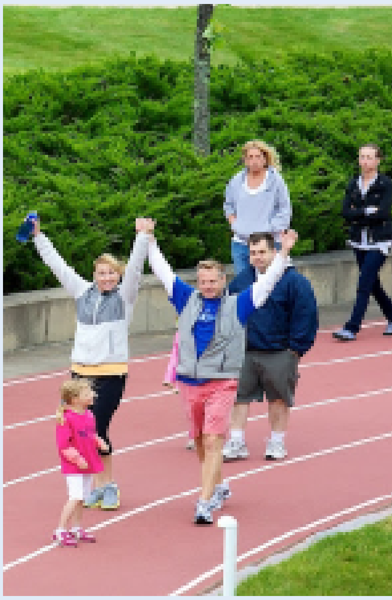
Not recognizing these early symptoms prevents people from beginning treatment that can buy time, even if currently no cure is known.

A full article about the 10 often-missed early signs of PD can be found on www.youngparkinsons.org.

Dr. Rezak is the medical director of APDA'S National Young Onset Center, and Illinois Information and Referral Center.

MEETING APDA'S MISSION ACROSS AMERICA

Each year thousands of people from coast to coast join in the largest grassroots walk-a-thon supporting scientists' efforts to learn more about the cause(s) of Parkinson's disease and ultimately to find the cure. More than $750,000 has been realized from walk-a-thons this year, (Two recent APDA walks, in Los Angeles, left, and Boston, right, netted $300,000), and there are more to come! Learn about upcoming APDA walks and other fund raising events across the country, or how to create your own event, at www.optimism4parkinsons.org or APDA's website.



APDA IN ATLANTA: ADDING HOPE TO AN HISTORIC CITY

APDA's mission in Georgia began in 1985 when it granted a charter to start the Atlanta Chapter.

In 1987 it was expanded to be the Georgia Chapter. Two years later, Ray Watts, MD,* with his wife Nancy, an RN, as coordinator, opened an Information & Referral (I&R) Center.

Dr. Watts with Mahlon DeLong, MD, received a grant for an APDA Center for Advanced Research (CAR) at Emory University School of Medicine in 1990. During the next quarter century, APDA's services to the people with Parkinson's disease, their families and caregivers in the state have grown to include 20 support groups; monthly public education meetings by Emory's physicians, researchers and therapists; exercise classes; a clinical trial promotion; and a "Caregiver Time Out Program" with the Alzheimer's Association.

To fund these resources, the chapter sponsors an annual gala, golf tournament, and this year participated in the Peachtree Road Race. It also is sponsoring a Mallorca, Spain raffle, and a dinner at Agatha's Mystery Theater in October. (See www.apdageorgia.org for program and event details.)

At the CAR, Dr. DeLong and his team of scientists work to integrate clinical care, research and education from the molecular/genetic level to innovative clinical trials of surgical techniques in advanced PD patients. For the past two years, the I&R center, CAR and Emory-Udall Parkinson's Disease Research Center have been putting together researchers and the PD community for round-table discussions about where the latest PD research currently is and where it is going. Researchers explain in non-technical language the whys and hows of many studies and how important it is for patients' and families' participation.

The People Who Make It Work

Dr. DeLong

Mahlon DeLong, MD
Director, APDA CAR
Member, APDA Scientific Advisory Board (SAB)

Dr. DeLong has been associated with APDA's Center for Advanced Research since its opening in 1990. He was also a professor of neurology and chairman of the neurology department for 13 years, leaving those positions in 2003 to head the development and building of the Emory School of Medicine Neuroscience Center.

Annemarie Schwarzkopf
President, Georgia Chapter

Ms. Schwarzkopf, 2nd from right, with Georgia Chapter board officers.

A Brown University graduate who began her working life in Europe, Ms. Schwarzkopf has headed the chapter for six years. Her business and socia-services experience in advertising, international sales and banking, and current position as community relations advisor for a Place for Mom, an Atlanta senior living community, are valuable assets in developing successful programs for people with PD.

**A native of Birmingham, Ala., Dr. Watts returned to his alma mater and today is senior vice president and dean of the University of Alabama School of Medicine – Birmingham, another APDA Center for Advanced Research. He is also a member of the SAB.*

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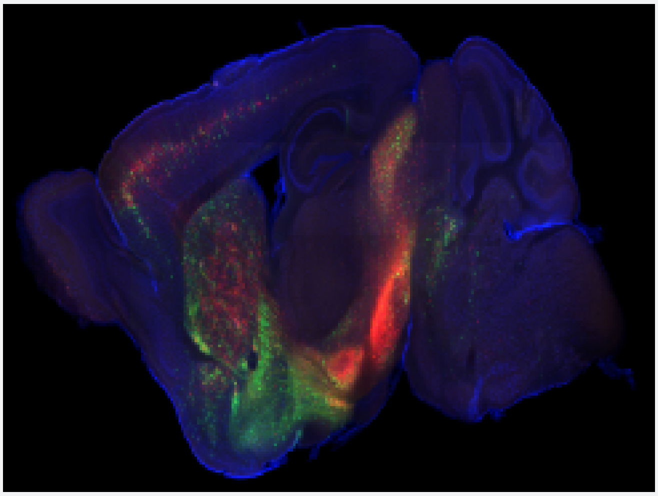
HARVARD RESEARCH TEAM REVEALS NEW DOPAMINE NEURON BEHAVIOR

A Harvard University research team has used a genetically modified version of the rabies virus to create the first-ever comprehensive list of inputs that directly connect dopamine neurons in two regions of the brain. Naoshige Uchida, PhD, associate professor of molecular and cellular biology and team leader, explained that the research was concentrated on the ventral tegmental area of the brain, known for processing reward, and the substantia nigra (SNc), known for motor control, and could one day lead to treatments for Parkinson's disease and addiction.

The study, which traced neural pathways in the brain and examined how other parts of the brain connect directly to dopamine neurons, was published in the June issue of the journal Neuron.

Following a complex protocol that included a fluorescent protein allowing them to track the virus in genetically engineered mice, the researchers found a wealth of connections to dopamine neurons, including some previously unknown areas.

"We found some new connections, and some that we suspected were there, but that were not well understood," Dr. Uchida said. "For example, we found that there are connections between the motor cortex and the SNc, which may be related to SNc dopamine neurons' role in motor control."



(Image courtesy of Mitsuko Watabe-Uchida and Sachie Ogawa)

Direct inputs to dopamine neurons: red areas represent neurons providing inputs to substantia nigra. Green areas show inputs to dopamine neurons in the ventral tegmental area.

More intriguing, according to the scientist, is the discovery that the subthalamic nucleus, a deep brain stimulation (DBS) target, preferentially connects to SNc neurons. "Why DBS works is not completely understood," he said. "There was speculation that DBS might work by inhibiting neurons in the subthalamic nucleus, but our findings suggest that because there is a direct connection between those neurons and dopamine neurons in the SNc, it is actually activating those neurons."

Dr. Uchida calls his work "a roadmap and a critical step for future investigations."

A summary and full text of this research can be found at www.cell.com/neuron/searchresults.

VETERANS UPDATES

VA STUDY CONFIRMS DBS MOVEMENT IMPROVEMENT VALUE

By Susan Gulas, RN

Patients with Parkinson's disease who undergo deep brain stimulation (DBS) can expect stable improvement in motor functions for a period of 36 months, according to a Department of Veterans Affairs study. The study results were published in the July 3, 2012 issue of the journal Neurology. The new report is based on 36 months of follow-up on 159 patients from the original group. Previous results from the study appeared in 2009 in the Journal of the American Medical Association and in the New England Journal of Medicine in 2010.

The Parkinson's Disease Research, Education and Clinical Center's (PADRECC's) recently developed Patient Education Brochures to provide veteran patients and families with information on the most common topics concerning Parkinson's disease. The brochures can be found on the National PADRECC and VA PD Consortium Website: http://www.parkinsons.va.gov/patients.asp. The titles of the brochures are "Exercise and Physical Activity," "Fall Prevention," "Parkinson's Disease Medications," "Motor Symptoms of Parkinson's Disease," "Non-Motor Symptoms of Parkinson's Disease," and "Agent Orange and Parkinson's Disease."

Ms. Gulas is the Coordinator of APDA's Veteran's Information & Referral Center in Reno, Nev.

FROM THE CHAIRMAN

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record of development and organizational successes, and we look forward to her leadership to continue and expand APDA's contributions to America's 1.5 million people with PD, their families and caregivers.

We all wish Joel Gerstel, who has admirably filled the top administrative post since 1995, a happy and healthy retirement.

APDA IN ATLANTA - ADDING HOPE IN THE CITY OF HISTORY

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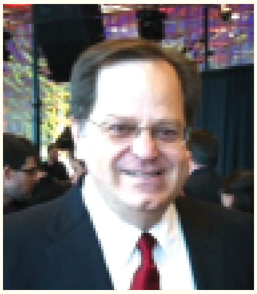
Lynn Ross, LMSW
Coordinator, I&R Center

Lynn Ross

Ms. Ross is only the third coordinator in the center's 25-year existence. She was graduated from Auburn (Ala.) University and received her MSW degree from Valdosta (Ga.) State University. Since joining Emory's movement disorders program five years ago, Lynn has developed a support group for caregivers of Progressive Supranuclear Palsy, one of only 21 such groups in the U.S. Her personal experience as a caregiver drives her special interest in helping those responsible for caring for someone with a chronic disorder.

Jorge Juncos, MD
Medical Director, I&R Center



Dr. Juncos, MD

Dr. Juncos, a Harvard Medical School-trained neurologist, has served as the center's medical director for almost a decade, and is an associate professor of neurology at the school of medicine. His particular expertise is in the evaluation and treatment of diagnostically difficult patients with PD and "Parkinson-plus" disorders.

EDUCATIONAL MATERIAL AND PATIENT SUPPORT RESOURCES

Information on Parkinson's Disease

APDA is the source of many free educational and patient/caregiver support materials. Most publications listed below can be downloaded from the website, www.apdaparkinson.org, publications page. Single copies are available by writing to the national office or calling 800-223-2732, faxing to 718-981-4399, or contacting any of the APDA I&R Centers.

Free subscription to a monthly e-newsletter and "Tip of the Month" feature are available on APDA's website home page. Lotsa Helping Hands, a private, caregiving coordination service that allows family, friends, neighbors and colleagues to create an online community to assist a caregiver with daily tasks can be reached by clicking the "Ease the Burden" button.

APDA's National Young Onset Center is located at Central DuPage Hospital, 25 North Winfield Road, Winfield, IL. and can be contacted at www.youngparkinsons.org, 877-223-3801, or info@youngparkinsons.org.

APDA's National Resource Center for Rehabilitation provides direct telephone (888-606-1688) and email (rehab@bu.edu) access to a licensed physical therapist at Boston University's Sargent College, for questions about exercise, information about programs in the caller's area and educational materials.

APDA's National Veterans Information & Referral Center is a centralized resource dedicated to supporting and improving the lives of veterans with Parkinson's disease, and can be contacted at 888-838-6259, ext. 1715 or www.reno.va.gov/parkinsons/parkinsons.asp.

BOOKLETS

(order by letter)

A. Parkinson's Disease Handbook
B. Young Parkinson's Handbook
C. Be Active
D. Speaking Effectively
E. Good Nutrition
F. Aquatic Exercise for Parkinson's Disease
G. My Mommy Has PD…But It's Okay!

SUPPLEMENTS

(order by number)

4. Keys to Caregiving
5. Hospitalization of a Parkinson's Patient
6. The Living Will and Durable Power of Attorney for Health Care
7. Parkinson's Disease and Oral Health
8. The Family Unit and Parkinson's
9. Maintaining Independence
10. The Challenge of Parkinson's Disease: Adapting to a Nursing Home
13. Medical Management of Parkinson's Disease and Medications Approved for Use in the USA
16. When Should Parkinson's Disease Patients Go to the Emergency Room?
17. Neuro-ophthalmology and PD
20. Fatigue in Parkinson's
22. Depression and Parkinson's
23. Incontinence and Parkinson's
24. Employment and Parkinson's
25. Constipation and Parkinson's
26. What is Dysphagia?
27. Cognitive Changes in PD

OTHER PUBLICATIONS

- Basic Information about Parkinson's Disease
- National Young Onset Center
- How to Start a Support Group
- Medications to Be Avoided or Used with Caution in PD
- 34 Helpful Hints to Improve the Quality of Life of People with Parkinson's
- The Importance of Having a Will

DVD

- Managing Parkinson's: Straight Talk and Honest Hope, Second Edition

AVAILABLE BY DOWNLOAD ONLY

at www.apdaparkinson.org

- Be Independent: Equipment and Suggestions for Daily Living
- Dr. Andrew Weil's Recommendations for Healthy Aging