



AMERICAN PARKINSON DISEASE ASSOCIATION

**WINTER
2013 ISSUE**



James P. Bennett Jr., MD, PhD (1983)
Chair, Department of Neurology,
Virginia Commonwealth University



G. Frederick Wooten, MD (1979)
Retired Chairman of Neurology,
University of Virginia School of Medicine



Ray L. Watts, MD (1989)
Sr. Vice President and Dean of the
School of Medicine,
University of Alabama at Birmingham



David Eidelberg, MD (1995)
Director for Neurosciences, Feinstein
Institute for Medical Research,
North Shore – Long Island Jewish
Health System



David G. Standaert, MD, PhD (1996)
Professor and Neurology Chair,
University of Alabama at Birmingham



Steven Fink, MD, PhD (deceased) (1984)
Professor and Chairman of Neurology,
Boston University School of Medicine

**APDA Cotzias Fellowships:
How one man's genius inspired
a program for hope.**

See page 4-5

FROM JOEL A. MIELE SR, CHAIRMAN

APDA's annual meeting last month was followed by a retirement luncheon honoring Joel Gerstel, our immediate past President & CEO, creating a physical picture of how our organization is transitioning into a new era. During Joel's celebration, we reminisced about the many successes and growth – in research, education, public awareness, and patient/caregiver support – achieved during his 30-year tenure, and at the meeting our new president, Leslie Chambers, shared her vision of "Moving Forward." APDA past and future sat together sharing their commitment to 1.5 million Parkinsonians and their loved ones.

That has always been APDA's formula for success – create a firm foundation and continue to build to comfort and support people with PD while working to find a cure. The process has been proven over and over as evidenced by our growth from one chapter to a national network of chapters, centers for advanced research, information & referral centers, and support groups that comprise the largest grassroots organization serving Americans with the disease.

In this issue you will read how the creation of the Dr. George C. Cotzias Fellowship in 1979, inspired by APDA-funded research that led to the discovery that high doses of L-Dopa effectively relieves

be an easy road; growth and expansion always include hard work and sacrifice, but it is a road that we are ready to travel – again. And, the longevity of loyalty such as Joel's 30 years and mirrored by board members, staff, scientists, and generous donors and supporters proves the journey worthwhile.

There is much excitement in the APDA organization today as we continue moving forward into a stronger tomorrow.



Chairman Joel A. Miele Sr. (left) leads the cake-cutting ceremony at former President & CEO Joel Gerstel's retirement luncheon.

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PD symptoms, has led to fostering the careers and contributions of 28 young scientists, six of whom subsequently have become department heads or higher at major academic and healthcare facilities. This mission-driven program to find a cure is another example that the APDA model of building upon proven success leads to greater success.

We realize this will not

NIH SEARCHES FOR PD BIOMARKERS

Emory University, Atlanta, an APDA Center for Advanced Research, is one of nine institutions being funded by the National Institutes of Health for a new initiative to accelerate finding PD biomarkers, changes in the body that can predict, diagnose or monitor a disease.

The Emory team will develop statistical tools to analyze data from brain imaging, genetic molecular and clinical tests to discover biomarkers that in combination can better predict the course of the disease.

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ASK THE DOCTOR

By Madaline B. Harrison, MD

Q: *Does memory loss seem to be a large component of Parkinson's or do Mirapex and/or other PD medications affect memory significantly?*

A: Parkinson's disease has a number of potential effects on memory and other aspects of cognition. One of the most common effects is on the ability to organize and use information, sometimes called executive function. This particularly affects tasks requiring multiple steps, or sequential processing. This problem, executive dysfunction, is distinct from the ability to retain new information. Most individuals with Parkinson's disease have the ability to learn new information but may have more difficulty retrieving it. Often simple cues or prompts will allow the individual to recall the material. This problem with retrieval is distinct from the more fundamental problem with retention seen in Alzheimer's disease, in which the individual has difficulty learning new material. Another common cognitive problem in Parkinson's disease is difficulty coming up with names or other words. This may occur without any other cognitive problems. Just as in individuals without Parkinson's disease, memory loss or dementia, in which the problem interferes with day-to-day activities, becomes more common as patients get older and is more likely to occur in those with Parkinson's disease.

Dopamine agonist medications such as Mirapex (pramipexole) or Requip (ropinirole), as well as other medications used in the treatment of Parkinson's disease such as amantadine or even high doses of Sinemet (carbidopa-levodopa) can cause confusion and this is more common in those with dementia. The medications themselves do not produce any permanent memory loss.



Dr. Madaline B. Harrison

Q: *Can sleep apnea produce Parkinson's symptoms, creating a form of misdiagnosis?*

A: Sleep disorders, including obstructive sleep apnea (OSA), are more common in Parkinson's disease, although not everyone with PD will develop them. Sleep apnea can cause a number of symptoms, including drowsiness during the day, headache, high blood pressure and high pressure in the blood vessels in the lungs. It would not be likely to cause Parkinson's symptoms but might result in more noticeable symptoms in someone with both PD and OSA.

Dr. Harrison is a professor of neurology at the University of Virginia School of Medicine and medical director of APDA's Virginia Information & Referral Center.

Materials concerning Parkinson's disease research and answers to readers' questions are solely for information and should not be used for treatment purposes, but for discussion with the patient's health care provider.

UNITY WALK

The place to be on Saturday, April 27 is in New York City's Central Park for the 19th Parkinson's Unity Walk, where thousands of people (and their pets) gather to raise awareness, dollars and bond in their commitment to finding the cure. One hundred percent of donations go to PD research.

Walking the .4 mile gentle park route is optional and the day is full of activities, information, and camaraderie.



Registration is from: 8:30 a.m. to 2 p.m. (There is no registration fee)

Booths open: 9 a.m. – 2 p.m.

Walk kick-off: 9:45 a.m.

Visit www.unitywalk.org for details.

APDA'S COTZIAS FELLOWSHIP:

The Great Seal of the United States announces, E Pluribus Unum meaning Out of Many - One.

By Heather A. Gray

An appropriate motto for APDA's George C. Cotzias, MD Fellowship could be just the opposite, From One Many, for it was the genius of one man that inspired the award that assists promising young neurologists in establishing careers in research, teaching and clinical services relevant to the problems, causes, prevention, diagnosis and treatment of Parkinson's disease and related neurological movement disorders. The fellowship pays \$80,000 annually for three years and is credited by many recipients as not only a high honor but also the stimulus to their future careers.

Dr. Cotzias was a pathfinder in the pharmacologic exploration of brain functions and the treatment of Parkinson's disease with levodopa. With APDA funding in the early



1960s he discovered the effectiveness of high doses of oral levodopa in treating PD symptoms, and it remains the standard treatment today. His work stimulated much of the current interest and research on neurological movement disorders.

Six fellowship recipients have achieved the position of chairman of the department of neurology at major U.S. academic and healthcare centers (see cover), including Ray L. Watts, former department

WHAT APDA'S COTZIAS FELLOWSHIP

"I recognize the APDA Cotzias Fellowship as one of the most important events in establishing my long-term commitment to Parkinson disease research. I received my award in 1996, which was a crucial moment in my career. I had just completed my movement disorders training and was a brand new assistant professor at Harvard Medical School. The financial support provided by the Cotzias Fellowship was very important in enabling me to develop my research directions, many of which I continue to follow. In addition, I believe that holding such a prestigious award was of great value to me in establishing collaborations and relationships within the PD research community." - **David G. Standaert, MD, PhD, University of Alabama at Birmingham**

"I remain grateful to APDA for funding my Cotzias Fellowship application. Because it is a significant award, I was able to develop lines of research relevant to Parkinson's disease that I would not have otherwise been able to support. Importantly, the data generated by the Cotzias award allowed me to successfully compete for an NIH R01 grant, which will allow me to continue to develop my science. Foundation grants such as this are critical to the development of new ideas and early scientific careers." - **David Hinkle, MD, PhD, University of Pittsburgh School of Medicine**

"As a previous Cotzias fellow, I know firsthand how much impact these awards can have. The Cotzias award from the APDA made it

A STIMULUS FOR PD RESEARCH

chairman at the University of Alabama – Birmingham (UAB) and currently Senior Vice President and Dean of the School of Medicine. As an engineering undergraduate at UAB, Dr. Watts's interest turned to medicine and he received his MD from Washington University, St. Louis. While a member of the Emory University (Atlanta) faculty, he was awarded a Cotzias in 1989 and with his colleagues built an internationally renowned movement disorders center there.

Introduced in 1979, the first Cotzias Fellowship was awarded to John H. Growdon, MD, who today is Director of the Memory and Movement Disorders Unit at Massachusetts General Hospital and a professor of neurology at Harvard University.

Dr. G. Frederick Wooten, the second Cotzias recipient, served as chairman of APDA's Scientific Advisory Board for 16 years, was the director of the Center for Advanced Research at the University of Virginia, where he was chairman of the department of neurology, functioned as the Virginia Information & Referral Center's medical director, and has been APDA's medical advisor for the past three years.

Like Dr. Wooten, other recipients have also continued an association with APDA, serving on its Scientific Advisory Board (Drs. Bennett, Watts, and Standaert), and as directors of APDA Centers for Advanced Research (Dr. Bennett, University of Virginia, and Dr. Standaert, UAB).

Ms. Gray is APDA's Scientific & Medical Affairs Assistant

HAS MEANT TO RECIPIENTS

possible for me to obtain equipment without which I would have been unable to continue my research. Perhaps even more importantly, I was reminded of the legacy of those investigators who preceded me, and was inspired to do my best to contribute to the effort to better understand Parkinson's disease. Both the financial support and the distinguished tradition represented by the Cotzias fellowship continue to play an important role in maintaining excellence in Parkinson's research." - **Madaline B. Harrison, MD, University of Virginia School of Medicine**

"The Cotzias Award has been instrumental in the development of my career as a physician-scientist focused on Parkinson's disease. This

grant allowed for me to have protected time to establish and develop my research endeavors in PD at the critical transition period from training into my first faculty position. As a result, this award has allowed my research to flourish and to be competitive for federally and privately funded grants. I am honored to be a recipient of this prestigious grant that has launched the careers of many distinguished PD researchers. Continued funding of this important grant is crucial to ensure that bright, young neurologists are continually attracted to and supported in pursuing research in PD." - **Talene Yacoubian, MD, PhD University of Alabama at Birmingham**

THERE ARE MANY PATHS TO APDA PARTNERSHIP

Parkinson's partnerships can take many paths, all with the common goal to ease the burden—find a cure:

Like 12-year-old Emily Whitmore of Gloucester, Mass., whose grandmother, Freda A. Whitmore, died of complications from PD four years ago, you can send a check directly to APDA. Emily's \$20 donation included a promise to contribute the same amount every year until a cure is found. "I really wish I could have talked to her more, but her Parkinson's disease got worse as she got older (she was diagnosed with Parkinson's at age 79 when I was born)," Emily wrote, "and, I would really like to help prevent that from happening to other grandmothers." She has also participated in two Massachusetts walk-a-thons.

Emily A. Whitmore donates in memory of her grandmother, Freda A. Whitmore.

All donations are acknowledged and, when made in memory or in honor of a person, the deceased's family or the honored individual is notified that such a gift has been made. The names of those in whose memory or honor gifts of \$50 or more have been made are listed in the quarterly newsletter.

Direct contributions may be made by mail, telephone or online at www.apdaparkinson.org.

Stock donations and other securities are another popular option.

The estate of composer Joseph Meyer ("California Here I Come," "If You Knew Susie Like I Know Susie," and "Crazy Rhythm") has been paying royalties for 25 years. Joseph and his wife Rosalyn's **estate planning** has contributed approximately \$100,000 to support APDA's mission to date and continues each time "My Honey's Lovin' Arms" is played.



APDA **charitable gift annuities** mean extra dollars in retirement for many who planned ahead and are receiving regular payments during their lifetime while assuring their future legacy to APDA. A charitable gift annuity can also generate valuable income tax benefits.

The easiest way to increase your support is to see if your company has a **matching gift program**. In most cases, this will double and in some instances even triple your personal contribution. APDA receives thousands of extra dollars every year through corporate programs such as matching gifts.

And, the most enjoyable path to partnership is to participate in one of APDA's awareness and **fundraising events** across the country. Events range from walk-a-thons to wine tastings to fashion shows and golf tournaments as well as educational programs and conferences. To find an event in your area go to <http://apdaparkinson.donordrive.com>

Information about all these paths to partnership is available by calling 800-223-2732 or sending an e-mail to kgwhitford@apdaparkinson.org.

APDA'S NATIONAL RESPONSE BENEFITS S.I. SUPPORT GROUP SANDY VICTIMS

Staten Island support groups' members impacted by super storm Sandy's destruction were presented gift cards that had been sent from APDA chapters and centers across the country. The event took place at National Headquarters last month.

During the storm's aftermath, several APDA staffers volunteered in devastated beach areas near the national headquarters and information materials were distributed at Red Cross and other disaster shelters on the Island. APDA coordinators in New Jersey and Long Island also provided information and support to people with Parkinson's disease during the crisis.



Emily Giorciai, national coordinator for support groups (left); Leslie A. Chambers, president & CEO (third from left); and Linda Ryan, RN, Staten Island coordinator (right), present support group members Michael Durso, (second from left), and Tania Galdorisi, and Nancy Bostic, (fourth and fifth from left), with gift card packages.

V.A. SWITCHES TO PAPERLESS CLAIMS

By Susan Gulas, RN

VA Goes To Paperless Claims System: The Department of Veterans Affairs has begun the nationwide transition to paperless processing of veterans' disability claims at its regional benefits processing offices. This transition is a part of building the foundation for VA's new electronic claims processing system, called Veterans Benefits Management System, which will hopefully help VA eliminate the backlog of disability claims by 2015. As of December 2012, 18 VA regional offices have implemented the new system and are beginning to process newly received compensation claims in a digital format. The VA is on track for full deployment of the system to the remaining 38 regional offices in 2013.

Website for Women Veterans: The Department of Veterans Affairs now has a website devoted strictly to women veterans. The website www.womenshealth.va.gov is available for women to find tools and resources for and about women veterans. It includes statistics, tips on wellness and healthy living, recent news, and links to publications, products, VA's Health Awareness and Culture Change campaigns, and VA's Facebook and Twitter pages. Also on the site is the recently developed Women Veterans Outreach Toolkit, which includes fact sheets on VA care and benefits, answers to frequently asked questions, brochures on VA services and health-care awareness materials

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



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 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 Rd., Winfield, Ill. and can be contacted at www.youngparkinsons.org, 877-223-3801, or apda@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 888-838-6256, 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