American Parkinson Disease Association

AMERICAN PARKINSON DISEASE ASSOCIATION

WINTER 2011

TELEMEDICINE:

PROVIDING PATIENT CENTERED PD CARE ANYWHERE

By Ray Dorsey, MD; Alexandra Gangler, BA, Kevin Biglan, MD, MPH

Deanna Ventura needed a Parkinson disease (PD) specialist. The 60-year-old New Hartford, N.Y. resident had been seeing a general neurologist for almost year after being diagnosed with PD in 2002. Living 150 miles away from the nearest specialists and unable to make the commute, Ms. Ventura struggled for a year, unhappy with her care and coping with her condition, before enrolling in a 6-month telemedicine study. The study was offered to residents of the community through the University of Rochester and Presbyterian Homes, providing access to a specialist through Web-based video conferencing, as opposed to traditional in-person visits.

Designed as a randomized, controlled pilot trial, the study evaluated the feasibility of providing patients with PD subspecialty care via telemedicine. Fourteen participants residing in the community and the nursing home were randomized to receive either telemedicine care or their usual care. At the study's conclusion, those receiving telemedicine care had completed 29 of 30 of their telemedicine visits as scheduled. Additionally, 13 of the 14 study participants opted to receive specialty care via telemedicine going forward. Those who received telemedicine care had significant

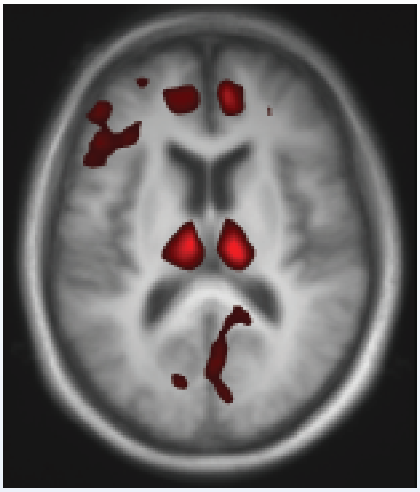
continued on page 6

in this ISSUE

APDA-FUNDED RESEARCH IN ST. LOUIS LEADS TO
BRAIN IMAGING BREAKTHROUGH

APDA-funded research at Washington University, St. Louis, has enabled neuroscientists using a new brain imaging technique to see an investigational PD drug get into a patient's brain and affect blood flow in several key structures, indicating the drug may be effective.

The study reported in The Journal of Neuroscience was led by Dr. Kevin Black, professor of psychiatry, radiology, neurology and neurobiology at the university, and demonstrates the capability of a magnetic resonance imaging (MRI) technique called per-



Perfusion MRI revealing where changes are occuring in response to drug.

continued on page 4

PRESIDENT'S MESSAGE

Dear Reader:

It's just about this time of year that I gird myself to stop dating checks and letters 2010. The reality of a change kicks in, and then I will be signing 2011 until next February.

It makes me think about how we respond to change. No one, except the young, is supposed to like it – most resisting it until it becomes the familiar and then fighting to preserve it. It's normal to like what is comfortable -- to want to keep it, but as we have seen in the past few years, change will come. It cannot be stopped, but even unwelcome change can benefit us.

When I became APDA's president, life was good. Our budget was hovering around $11 million. We were funding more research than ever before, opening additional centers, offering new services. Then came the "crash." (In my darker moments, I think it was waiting for me to accept the gavel.) Contributions drastically decreased, traditional funders cut or stopped support, postal rates and other costs increased almost in direct proportion to income decreases. Fortunately, a wisely conservative financial plan spared APDA many of the hardships of some more liberal spending and investing non-for-profits, but times were difficult. Costs had to be cut.

Winter 2011
Issue No. 93 © 2011

Published quarterly by the
American Parkinson
Disease Association, Inc.
135 Parkinson Ave.
Staten Island, N.Y. 10305
800-223-2732
apda@apdaparkinson.org
www.apdaparkinson.org

President
Joel A. Miele Sr., P.E.

Executive Director
Joel Gerstel

Editors
Michele Popadynec, RN
Kathryn G. Whitford

National Young Onset Center
25 N. Winfield Rd.
Winfield, Ill. 60190
877-223-3801
apda@youngparkinsons.org
www.youngparkinsons.org

There's a good part to this, if you are asking. Yes, we were forced to do more with less. We found new programs and services we could offer that were less expensive, but equally needed and welcomed. We contracted with Lotsa Helping Hands, an electronic program that provides a free tool to help caregivers organize their volunteered help. We worked with Boston University's Sargent College and created the first Parkinson's rehabilitation resource including a free hot line and Web site. We entered the electronic world, which has introduced other strong venue sources. Our "Have A Question About PD?" Web site feature is providing guidance to hundreds of people around the world at no cost to them and at minimal cost to us.

And as with all scientific bell-curves, the slope is again on the ascent, but lessons have been learned. We have seen true friends who continued supporting us even if it had to be at a lesser level, and found new ones, who recognized the value of our mission. We have a 100 percent board-giving program, and continue to carry out our mission of caring through the largest grassroots PD organization in the country.

So, while we are a little harried and with a few more grey hairs, we are thankful. Our attitude is gratitude.

Have a happy and prosperous New Year.

Joel A. Miele Sr., PE
President

Charlene Allo Named Director of Chapter Relations

Charlene Allo has been appointed APDA's director of chapter relations. Charlene joined the association in 1995 as executive assistant and subsequently was named coordinator of special events, a function she will continue to fill. She will be responsible for coordinating the activities of APDA's 46 chapters across the United States with the association's national objectives and initiatives.

ASK the DOCTOR

Q: My father and uncle had Parkinson's disease. What are my chances of having it also?

A: About eighty-five percent of people with PD do not have any other relative with the disease, and consequently a family history of PD is not common. Nevertheless, a family history of PD is the strongest known risk factor for PD. When several people in the same family have PD, there is a stronger chance that one of the genes that I mentioned above may be present.

In my lab, we studied about 500 families where two or more members were affected with PD. Not one of those families had a mutation in alpha-synuclein, and only 7 percent had a LRRK2 mutation. The Parkin gene is a bit different; one must have two copies of the gene mutation. Usually we do not see that form of PD showing up in two-generations. Further, the Parkin form has an unusually early onset, so the main context when Parkin testing might be in order is for young onset PD.

Q: Is there any new research about genetic predisposition to PD?

A: The understanding of the role of genetics in Parkinson's disease is progressing extremely quickly, and has advanced particularly rapidly in the last year with the publication of eight very large genetic studies in PD. More than 12,000 individuals with PD have now been studied using this new genetic technology to identify the genes that influence the risk for developing PD. At least six genes have been clearly implicated and a similar number are very strongly implicated and most of these will also likely turn out to be important.

The main focus of these studies is to understand what is causing PD, which will help us to identify specific biological deficits that might be targets for developing new treatments. This kind of research can take a long time but clearly the understanding of why people get heart disease (cigarette smoking, hypertension, high cholesterol, poor diet, diabetes, obesity, etc. – most of which have a strong genetic basis) has been the main method to help reduce the frequency of heart attacks. Knowing what causes PD will unquestionably be similarly important.

Richard Myers, PhD, Director, Neurogenetics Laboratry, Boston University School of Medicine and member of APDA's Scientific Advisory Board.

Q: Is there a test to learn if I have a Parkinson's disease gene?

A: The genes implicated in Parkinson's disease fall into two main categories:

1. Rare gene mutations with powerful effects, which can cause PD.
2. Gene variants that contribute to PD risk when combined with other factors (either other genes or environmental exposures).

In the first category, there are primarily three genes to consider: 1. alpha-synuclein (also known as Park1), 2. LRRK2 (Park8), and 3. Parkin (Park2). A few other very rare genetic mutations in this category are known, DJ-1 and Pink1 for example. There are actual genetic tests for the genes in this category.

The second category includes the genes MAPT (microtubule associated protein tau), GAK, (cyclin G-associated kinase), GBA (glucocerebrosidase-beta acid), SLC41A1, and a few others. Currently, there

continued on page 5

DEPRESSION AND ANXIETY Part 2

By Annette Schrag MD, PhD

The first important issue in managing depression and anxiety in a person with PD is to determine whether the symptoms occur solely in off-periods. If so, adjustment of antiparkinsonian medication is required and is usually successful.

If depression or anxiety symptoms are not from nonmotor fluctuations, the severity of symptoms should be determined to assess the need for treatment. In most cases with mild depression, non-pharmacological intervention is the treatment of choice, with treatments ranging from counseling and patient education to cognitive-behavioral therapy.

There are several medication approaches to treatment:

Dopaminergic: As many patients will already be on dopaminergic medication for improvement of motor symptoms, optimization of existing treatment may be pragmatic first step. Dopaminergic medications have been suggested to improve depressive symptoms in PD.

Psychotropic: There is a suggestion that antidepressant medications in PD are less effective than in depressed non-PD patients, although older patients and those with major depression may have a better response.

Consideration should be given to the potential side effects related to these medications, particularly in the elderly, their possible interaction with other drugs resulting in variations in plasma concentrations, reports of exacerbation of motor function and their potential to exacerbate nonmotor and dopaminergic drug-related complications of the disease.

There has been no systematic assessment of anxiolytic treatment in PD. The SSRI are currently favored as treatment of anxiety disorders in PD but their therapeutic efficacy is yet to be demonstrated. Benzodiazepines can increase the risk of falls and cognitive, autonomic and sleep-related side effects and should be used with caution.

(Part I of Dr. Schrag's article appeared in the Fall 2010 issue and can be downloaded from www.apdaparkinson.org, or ordered by calling 800-223-2732.)

Dr. Schrag is a member of the faculty of University College's Department of Clinical Neurosciences, London.

APDA-FUNDED RESEARCH IN ST. LOUIS LEADS TO BRAIN IMAGING BREAKTHROUGH

continued from page 1

fusion imaging to measure a drug's effect on the dopamine system in the human brain. The drug, SYN-115, can affect dopamine systems indirectly. The perfusion MRI reveals where changes occur in the brain in response to the new drug.

Dr. Joel Perlmutter, director of the Washington University Center for Advanced Research, one of nine such APDA centers across the country, hailed the new technique as an approach that can lead to new and faster ways to evaluate new drug therapies for PD.

The study was funded by APDA, APDA's St. Louis Chapter, and the National Institutes of Health.

YOUNG ONSET PARKINSON CONFERENCE A BIG SUCCESS

By Julie Sacks, LCSW
Director, APDA National Young Onset Center

The series of Young Onset Parkinson Conferences, co-sponsored last year by APDA and the National Parkinson's Foundation, was a success in every respect and will continue in 2011. The regional events not only provide an opportunity for learning and camaraderie, but also the live Webcasts allow people to participate nationally and internationally and share in the sense of community the events foster.
The next conference will be held in Des Moines, Iowa on June 18, in conjunction with the state's annual Parkinson's disease symposium.

SAVE THE DATE

YOUNG ONSET PARKINSON CONFERENCE
Des Moines, Iowa • June 17-18, 2011

AROUND THE COUNTRY

Unity Walk to Honor Arizona Chapter Member

Congratulations to Jean Burns, who will receive the Alan Bonander Humanitarian Award at this year's Unity Walk, April 16, in Central Park, N.Y. Jean has been an active member of APDA's Arizona chapter and was honored as its 2006 distinguished volunteer. She is also the 2009 recipient of the Parkinson's Action Network's Milly Kondracke Award.

Shorty Turns 40 in San Francisco

From Kathryn Collier's "Shorty Turns Forty" Web site campaign.

There aren't many women who'll announce aging another decade, but that's exactly what Kathryn Collier, sister of New Jersey Chapter president, Vicki Collier, did on Dec, 30, and launched a year-long fundraiser/awareness campaign with all proceeds to support APDA's research program. To date, Kathryn's aging has contributed $17,000 via www.shortyturnsforty.org.

South Florida Raises the Bar for Research

Hannah Bentz rides Crystal during Jump for a Cause.

APDA chapters have walked, danced, dined, played golf, showed fashions, sailed, rocked, and even raced gerbils, but only the South Florida Chapter has horsed around to support research and awareness. Designed by young equestrian Hannah Rachel Bentz, as her mitzvah project, Jump for a Cause, brought more than 200 people to the Jim Brandon Equestrian Center in West Palm Beach, where Bobbi Rottman's team, Buttonwood Street, took top kudos. Hannah dedicated the project to Rabbi Merle Singer, who was diagnosed with PD shortly after his retirement. And good followed good. Less than a week later, Michael Perez, director of the spa at the Four Seasons Resort, Palm Beach, conducted a silent auction in honor of Hanna, adding nicely to the event's success.

Going Latin in Wisconsin

The benefit of dance has been well established, including APDA-funded research that launched the Argentine Tango as a rehabilitation aid. In Wisconsin it is Zumba Gold, a version of the popular Zumba, a Latin-inspired workout. APDA's Wisconsin Chapter sponsors weekly free classes at the Harbor Athletic Club, Middleton.

ASK the DOCTOR

continued from page 3

are not genetic tests for this category of genes, and a lot more work to identify what goes wrong in these genes will need to be done for them.

Dr. Richard Myers is a PhD medical geneticist and professor of neurology at Boston University. He has been a member of the APDA Scientific Advisory Board since 1996. His laboratory has been studying the genetics of PD for almost 20 years.

TELEMEDICINE CAN MAKE A DIFFERENCE

continued from page 1

improvements in their quality of life and in their symptoms compared to those who received usual care. Ms. Ventura stated, “I truly feel that I got the type of attention that I needed and was not accessible to me because of the area I lived.” The study, which was recently published in Movement Disorders, showed that providing subspecialty care remotely is, in fact, very feasible.

The Growing PD Burden

Parkinson’s disease is a chronic condition with a burden growing both in the United States and globally. Studies have shown that people live for an average of 14 years, or roughly one fifth of their lives, with the disease, and that 40 percent of these individuals will require nursing home care at some point in time.

In 2005, studies estimated that there were 4 million people in the world’s most populous countries with PD. By 2030, this number will more than double. PD is readily treatable with affordable medications that significantly decrease risk of death, the vast majority of those affected by the disease globally has not sought or received treatment.

Another major challenge, as demonstrated by Ms. Ventura’s case, is that access to a specialist is currently very limited. As with any chronic condition, increased access to specialists can improve patient care and outcomes, and ultimately lead to a better quality of life. In a study of 300 individuals with PD across the United States, those who saw a specialist were three times more likely to be satisfied with their care than those who saw a general neurologist.

Telemedicine: How it Works and How it Can Help

With so many hurdles that accompany this burdensome condition, it begs the question: is there a way to provide high-quality, patient-centered care to individuals with PD regardless of their location? The answer is yes. Through simple Web-based video conferencing, telemedicine visits can extend the reach of care into the home. A readily available, feasible and inexpensive solution, a “virtual house call” requires nothing more than a computer with broadband Internet access to provide care to anyone anywhere. Most visits that have been carried out through studies have used a simple set-up such as Skype with encryption, the same technology grandparents use to talk to their grandchildren every day.

Furthermore, telemedicine can be the solution to several issues surrounding rising health care costs. The current model for receiving care requires patients to travel miles and, in most cases, probably pay more for transportation costs than for the actual visit. These in-person visits are an enormous loss of labor, time and productivity for both the patients and caregivers. Proponents say that telemedicine technology can increase cost efficiency, reduce transportation expenses, improve patient access to specialists, and ultimately improve the quality of care and the quality of life for patients with chronic conditions like PD.

Going Forward, What You Can Do

Despite its value, Medicare and other healthcare insurers currently do not cover most telemedicine services for 80 percent of people who could benefit. To bring about change, in hopes of providing patient-centered care to people with PD anywhere they live, advocates are urging more awarness. Some of the prominent issues that must be overcome before implementing the telemedicine model include:

- Obtaining insurance reimbursement for telemedicine visits at both the state and federal level
- Expanding geographical coverage for reimbursement to all communities and to your home
- Addressing state licensure barriers for physicians

Proposed legislation includes the Medicare Telehealth Enhancement Act of 2009 (H.R.2068). One source is the American Telemedicine Association at www.americantelemed.org.

The author can be contacted via e-mail: Dr. Dorsey at PDMDfeedback@jhmi.edu or Dr. Biglan at Nicholas_Scoglio@URMC.Rochester.edu.

VETERANS AFFAIRS PADRECC CENTERS PROVIDE VETERANS WITH EXPERT CARE

By Rebecca Martine, MSN, RN, PMHCNS

When the Department of Veterans Affairs (VA) launched its Parkinson's Disease Research, Education and Clinical Centers (PADRECC) in Philadelphia, Richmond, Houston, West Los Angeles, San Francisco and Portland/Seattle in 2001, 80,000 veterans with Parkinson's disease were given a way to manage their care better. The PADRECCs provide a system for direct access to pharmacy benefits; physical, occupational, and speech therapies; medical equipment; surgical services and other valuable resources.

Two years later the PADRECCs introduced the National VA Parkinson's Disease Consortium in an effort to promote PD awareness throughout the VA. This initiative focuses on professional networking, mentorship, and training. The consortium is composed of more than 225 members including VA physicians, nurses, pharmacists, social workers, physical and occupational therpists and other allied health professional.

To broaden the impact of its mission, PADRECC launched the Consortium Center Network in 2006., a network of 51 designated PD clinics across the country providing veterans convenient access to specialty care. Centers' staff include movement disorder specialists and other neurologic healthcare providers.

All veterans enrolled in the VA Healthcare System are eligible for PADRECC or Consortium Center services. Additional information including locations of centers and how to make an appointment is available at www.parkinsons.va.gov. or by calling 800-949-1001 ext. 2749.

Ms. Martine is chairperson of the National VA PD Consortium, and associate director of education at the Philadelphia PADRECC.

PD COMMUNITY LOSES TWO LEADERS

Jim Mauer

Two of APDA's most selfless champions for the Parkinson's community have succumbed to complications from the disease.

Jim Mauer, diagnosed in 1990 and founding president of APDA's Massachusetts Chapter, became a giant in creating awareness across New England. Announcing his death, Cathi Thomas, APDA's Boston Information & Referral Center coordinator, said, "Jim was able to utilize his personal charisma, his keen marketing sense, and his unending commitment to Parkinson's to network with the medical, research, and patient-advocate communities. He always had time to make a positive difference in someone's life." Jim was 78 years old and survived by his wife Vicki, and children James, John, and Mollie Sorenson.

Margaret Miller was a volunteer leader in the Atlanta, Ga. public school system when she was diagnosed in 1994. She then turned her efforts head-on and full-steam-ahead, totally involved and determined to "fight back" against the devastating disease. Margaret became heavily involved in fundraising for research and served on APDA's Georgia Chapter's executive board for 10 years. "Her positive attitude and smile touched so many friends – not only in the Parkinson's community but everyone with whom she came in contact," remembers Kathy Edwards, chapter director. She leaves her husband Carl and three daughters, Cameron Tiedje, Robin, and Courtney Sanders. She was 74 years old.

EDUCATIONAL MATERIAL

AND PATIENT SUPPORT RESOURCES

APDA is the source of a variety of free educational and patient/caregiver support materials. Most publications listed below can be downloaded from the Web site, 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 Information & Referral Centers throughout the United States.

Free subscription to a monthly e-newsletter and "Tip of the Month" feature are available on APDA's Web site 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 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 College of Health and Rehabilitation Sciences: Sargent College, to answer questions about exercise, provide information about programs in the caller's area and provide educational materials.

BOOKLETS

(order by letter)

A. Parkinson's Disease Handbook
B. Young Parkinson's Handbook
C. Be Active
D. Be Independent*
E. Speaking Effectively
F. Good Nutrition
G. Aquatic Exercise for Parkinson's Disease
H. 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
21. Dr. Andrew Weil's Recommendations for Healthy Aging
22. Depression and Parkinson's
23. Incontinence and Parkinson's
24. Employment and Parkinson's
25. Constipation and Parkinson's

FLYERS

- Basic Information about Parkinson's Disease
- National Young Onset Center
- 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

WEB SITES

- www.apdaparkinson.org
- www.youngparkinsons.org

DVD

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

Available by downloading from www.apdaparkinson.org

The printing and distribution of this newsletter are supported by a grant from Novartis