APDA 50 Years
TO EASE THE BURDEN
TO FIND THE CURE
American Parkinson Disease Association

AMERICAN PARKINSON DISEASE ASSOCIATION

SUMMER 2011

APDA-FUNDED RESEARCH AT UCLA LINKS AMBIENT PESTICIDE EXPOSURE TO PD

APDA's Center for Advanced Research at the UCLA School of Medicine, under the direction of Marie-Francoise Chesselet, MD, PhD, has been in the forefront of research linking environmental factors to Parkinson's disease (PD). In April 2009 its efforts confirmed a link between PD and two commonly used chemicals for pest control, the fungicide maneb and herbicide paraquat, finding a 75 percent increased PD risk for people exposed to the chemicals.

Most recently a follow-up study by a team including Jeff Bronstein, MD, PhD, director of APDA's Los Angeles Information & Referral Center, and APDA research grant recipient Beate Ritz, MD, PhD, found a third pesticide, ziram, in the pathology, and discovered that non-farm workers who worked near but not in the fields were also affected. Anthony Wang, Sadie Costello, Myles Cockburn and Xinbo Zhang were also on the team.

Dr. Ritz noted, "This stuff drifts. It's borne by the wind and can wind up on plants and animals, float into open doorways or kitchen windows – up to several hundred meters from the fields."

The nine-year study in California's fertile central valley, a heavily agricultural area, included 362 people with PD and 341 controls who lived in the region. Historical, occupational and residential addresses were fed into a geographic information system-based tool developed by Dr. Ritz and her colleagues. Results reaffirmed what previous research had found and suggested that the critical window of exposure to toxicants may have occurred years before the onset of motor symptoms appeared and the PD diagnosis was made.

The study was reported in the European Journal of Epidemiology.

IN THIS ISSUE

OPTIMISM CAN TAKE YOU ANYWHERE

Read how this man on this boat plans to raise awareness and dollars for PD research. *Page 4*

FROM THE CHAIRMAN

While you are enjoying the "lazy days of summer," APDA is nearing the end of its fiscal year and looking forward to a new year beginning Sept. 1.

We are beginning the year with a new position of president & CEO. Joel Gerstel, who has served APDA for more than two decades, was given the new title at our last directors meeting in May. This change is in keeping with most corporate structures and assures a continuity of professional leadership of the organization's operations as the board chairman changes every six years. It is also in recognition of Joel's many years of astute and loyal leadership.

We are also looking to revitalize our research program, which because of the economic downturn of the past several years, was limited to our nine centers for advanced research, outstanding multi-year grants and medical student summer internships. They are all worthy programs and have resulted in valuable research during the past two years. I call to your attention the article on page 1, of major findings about the link between PD and pesticides, including the discovery of a third agricultural chemical associated with significant increased risk of developing the disease.

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I wish you a happy, relaxing remainder of the summer and assure you that APDA is working throughout the year to "Ease the Burden – Find the Cure."

Joel A. Miele Sr., PE

FROM THE PRESIDENT & CEO

"A rose by any other name." That's what comes to mind when I look at my newly changed title at APDA.

I am honored by the action of the board of directors, but the challenges of leadership of any organization with the mission to find a cure for a disease without a known cause, no definitive diagnostic test, and 1.5 million affected Americans and their caregivers, remain the same.

Rather than losing hope, these challenges make us more determined to muster our resources and direct our energies every day.

APDA's unique dual mission of funding research and providing support and education to people with the disease and their caregivers covers the gamut of needs. Our outstanding Scientific Advisory Board and our national network of healthcare professionals and dedicated volunteers assure that the research we fund is the most promising and the support that we give is the best possible.

I look forward to continuing this course that has made APDA the largest grassroots organization serving America's Parkinson's disease community – and being part of the celebration when we find the cure.

Joel Gerstel

ASK THE DOCTOR

By Joseph Friedman, MD

Dr. Joseph Friedman

Runny nose

Q: For many years I have had a runny nose that has become worse over time, but never gave it a thought in relation to having Parkinson's disease until I heard a member of my support group say he has the same problem. Are the two related?

A: Rhinorrhea is the technical term for "runny nose." I learned from the nurse practitioner who worked with me, Carol Jacques, that a lot of our PD patients complained that their noses ran all the time. I didn't pay this any attention until one of my patients told me that he could get used to being in a wheelchair, but the runny nose was driving him nuts. So I decided to study this to see if it was a problem. And I found out that it was. About half of my PD patients reported that they had a runny nose, all year round. Many had seen ear, nose, and throat doctors, or had been told they had allergies. Since I published my observations, based on patients in Rhode Island, it has been confirmed in Florida and Michigan. We think that it is due to PD affecting the nerves that go to the inside of the nose. Normally the nerves that cause mucous secretion are balanced by the ones that keep the nose dry, but we think that the nerves that reduce the mucous production are injured by the PD. I consider ipratropium nasal spray 0.03% helpful, but this has never been proven.

Reminding a patient

Q: My father has PD and we read everything we can about how to make his life as good as possible without nagging. What would you suggest as the most important thing we, as a family, should emphasize and encourage him to do?

A: Nagging is an important issue. As a doctor I usually find it impossible to distinguish "reminding" from "nagging," and when family members or patients ask me to help, I'm usually not able to. When patients are reminded to sit or stand up straight, they can do this, but as soon as they think about something other than their posture, it immediately reverts to the way it was. Reminding does not translate into a change. It becomes nagging. What about reminding patients who might fall to use a walker? On the one hand if a fall or two doesn't make a person cautious, what will? On the other hand, how can you let your loved one risk another fall that might cause a hip fracture? Should you remind the patient to swing her arms when she walks? She'll stop doing it once she starts thinking about how to turn around without losing her balance. So, where does reminding cross over into nagging?

I think it happens at different places for different people. Overall, unless the issue is safety or exercise, I think the best approach is to ask the patient if she wants to be reminded. "Do you want me to remind you to stand up straight? Do you want me to remind you to swing your arms? Do you want me to remind you to hold the phone closer to your mouth?" However, patients should be reminded to use their walker if it's needed, to put only a small amount of food into the mouth, to exercise every day, etc.

Protein in the diet

Q: I was diagnosed seven years ago and have followed all the directions about medications, diet, exercise, and staying socially active. I restrict my protein consumption because I have read that protein blocks Levodopa absorption, but sometimes I have a "fat attack" and have to have a hamburger, fries and a milkshake. I have never seen any difference in how my medication works after eating all the wrong foods, and wonder if I am denying myself something I like for no reason.

A: There are clear data that certain amino acids, which are the breakdown products

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TIME, TIDE AND BOB PRESTON WAIT ON NO MAN OR DISEASE

***Narragansett, R.I.* –** It is 2006. Bob Preston, a young successful insurance-business owner who has a nice house, two great children, "the world's best wife," and a boat featured in the centerfold of MotorBoating Magazine is beginning to slow down and doctors suspect Lyme disease. Test results, however, prove negative. Only a “ratcheting” in his wrists gives them a clue, and at 47 years old, Bob is diagnosed with Parkinson’s disease.

In the five years since then, Bob has taken the disease head-on. “It is what it is. I live in the moment. I still have the same sense of humor and I don’t plan to let life pass me by.”

And to prove it, Bob, who has a 50-ton commercial vessel captain’s license, and his admiral, wife Becky, last month launched the “Optimism Can Take You Anywhere Tour,” an approximately 5,000-mile round trip excursion from northern Maine to the Florida Keys on their 37-foot Back Cove motor yacht, to raise awareness and funds for PD research.

He has experience in this as well.

When first diagnosed, he learned of APDA’s Rhode Island Chapter, which, like most non-profits, needed funds. According to the Rhode Island Information & Referral Center coordinator, Mary Ellen Thiboudeau, “Bob set out on his own to raise $10,000 for the chapter in 90 days. He was so determined and focused on hitting that 10K goal that he raised more than $53,000! Not bad in a tough economy!”

“I didn’t know anything about fundraising,” he confesses, “but I had my Rolodex with 752 names.” That, along with his ability to talk with people and dogged determination, made the difference.

Now he is setting his sights to increase donations to $150,000 for Parkinson’s research. He expects the boat trip will last until next spring. The odyssey will include stops along the way to meet with other APDA chapter people, give media interviews to heighten awareness and to raise research funds.

As he progresses along the East Coast, you can follow on APDA's website, his Facebook page (Bob Preston Cure PD) and on Twitter @CurePD.

To support Bob's Optimism Tour and APDA -FUND A CURE visit **http://apdaparkinson.donordrive.com/participant/bobprestonpd.**

ABBOTT REPORTS POSITIVE INTERIM RESULTS ON L-C GEL PUMP DELIVERY SYSTEM

(Follow up on an article in the last newsletter about the clinical trial of a new levodopa-carbidopa intestinal gel delivery system).

Abbott Laboratories, the system’s manufacturer, reported a decrease in “off” time and increase in “on” time without troublesome dyskinesias after 12 weeks of a 54-week Phase III open-label study. The trial is taking place at multiple sites across the country. The report was presented at the June International Congress of Parkinson’s Disease and Movement Disorders in Toronto.

The 192 patients with advanced PD reported an average of 3.9 fewer “off” hours and 4.6 additional “on” time hours. The surgical procedure required for the pump was reported responsible for most of the adverse events reported by 168 patients. The most common adverse effects were abdominal pain, complications of device insertion, and procedural pain.

The original article in the Spring 2011 issue may be read on the publications page at www.apdaparkinson.org. Additional information is available by searching the title, “Study of Efficacy, Safety and Tolerability of Levodopa-Carbidopa Intestinal Gel in Levodopa-Responsive Parkinson’s Participants” on the Web.

WHY AND WHEN: THE MAJOR QUESTIONS IN CONSIDERING PD GENETIC TESTING

By Richard Myers, PhD

I am relying on my experience with Huntington disease (HD) testing, which admittedly is a bit different because it usually has a younger onset age (from age 30 to 50). Nonetheless, because testing does not influence the kind of medical treatment one receives for either PD or HD, or the expected course of the disease, it is important to consider carefully why one might seek to be tested. In HD, testing is commonly not done simply out of curiosity, but rather because there is someone else who the individual feels should know, such as a prospective spouse or fiancé, or in some cases a young adult child who is considering getting married. Certainly this can be the case for PD as well.

Occasionally financial planning is given as a reason for testing. It is important to understand that the available tests are limited to only a few rare familial forms of PD. Thus, for PD, a negative test result may not mean that PD has been ruled out. Finally, with older onset disease such as PD, good financial planning for the eventuality of a possible chronic disease can be done without testing.

In some instances, a neurologist may have reason to order a Parkin gene test when an individual has a young onset. There are some families where it is known that members carry either the alpha-synuclein or the LRRK2 forms of PD and in some instances individuals want to know if they may be likely to develop PD. Nevertheless, because it does not influence decisions around medical care, genetic testing should be approached carefully.

The known “testable” PD genes account for only about 10 percent of “familial PD” (families with two or more members diagnosed), and one should never feel pressured or obligated to be tested. When in doubt, it is best to postpone testing until one can arrive at a clear understanding of how the test result, regardless of whether it is positive or negative, will be beneficial.

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

SERVICES GROW AT APDA YOUNG ONSET CENTER

APDA’s National Young Onset Center is growing and so are its services. We invite you to contribute to that growth by sharing your knowledge and experience with us and with one another.

- **Read and comment on our blog.** Written by an experienced neuropsychologist, this blog offers readers a different perspective on living with and managing Parkinson’s disease. Written with the challenges of younger individuals and families in mind, many of the issues Dr. Paul Short addresses such as confidence and competence, depression and anxiety, relationships and family dynamics are concerns for people of all ages.
- **Discover or share a resource.** It’s not always easy to find or afford the things that can improve quality of life, especially if you’re living on a fixed income. Our interactive, online Resource Guide was created to resolve this problem. It features organizations that make low-cost or no-cost services available to people with Parkinson’s. Current categories include physical and mental health, employment and insurance as well as financial and legal services.

NEWS FROM APDA VETERANS' CENTER

APDA's Veterans' Center reports that the Department of Veterans Affairs has developed the National Caregiver Support Line for family members, loved ones, or friends who provide care for veterans living with the effects of war, disability, chronic illness or aging. The toll-free telephone number is 855-260-3274. For more information visit www.caregiver.va.gov. The website provides help in finding information and support by area code, guidelines for staying strong, a caregivers' tool box, and available caregiver services including new services for caregivers or post 9/11 veterans.

SCIENTISTS IDENTIFY SEVEN WORST NON-MOTOR PD SYMPTOMS

Scientists in the United Kingdom have identified the seven worst non-motor symptoms in Parkinson's disease (PD).

Addressing the fact that, until recently, non-motor symptoms have received relatively little attention, David Gallagher, MRCP, and Drs. Andrew Lees and Anette Schrag, assessed the impact of non-motor symptoms on 94 patient-participants. Their findings were published in the journal Movement Disorders.

The order and frequency of the most common symptoms are:

- Urinary and gastrointestinal symptoms (84 percent)
- Mood (74 percent)
- Fatigue (74 percent)
- Daytime somnolence (65 percent)
- Pain (56 percent)
- Nighttime sleep problems (55 percent)
- Psychosis (55 percent)

Of all PD symptoms, those having the greatest impact on quality of life are depression followed by fatigue, thermoregulatory, gastrointestinal and cardiovascular autonomic function, daytime somnolence and urinary problems.

The scientists also found that while psychiatric problems are increasingly being documented, many symptoms, particularly those perceived as embarrassing or unrelated, remain underreported.

STUDY SHOWS THAT WOMEN BENEFIT FROM SOME ANTIOXIDANT VITAMINS

A six-year study involving more than 600 volunteers has concluded that women who consumed higher amounts of vitamin E and ß-carotene (the precursor of vitamin A) were significantly associated with reduced risk of Parkinson's disease. The reduced risk was down to 45 percent for vitamin E, and down to 56 percent for ß-carotene. No relationship occurred in men.

The research, reported in the European Journal of Neurology, investigated the relationship of the dietary intake of antioxidant vitamins and the risk of PD. It was conducted at Fukuoka University, Osaka, Japan, by 14 scientists and the Fukuoka Kinki Parkinson's Disease Study Group, and adjusted for gender, age, region of residence, pack-years of smoking, years of education, body mass index, dietary intake of cholesterol, alcohol, total dairy products and coffee, and the dietary glycemic index.

No relationships were found between PD risk and vitamin C, a-carotene, other vegetables, cryptoxanthin, or fruit.

Vitamin E is found in mustard greens, Swiss chard, spinach, kale and nuts; ß-carotene-rich foods are sweet potatoes, carrots, peppers, kale and spinach.

ASK THE DOCTOR

Continued from page 3

of proteins interfere both with absorption of L-Dopa from the gut into the blood and from the blood into the brain. It has nothing to do with all the other PD medications and has nothing to do with PD itself. However, it is uncommon for this actually to affect patients. I always tell people to do the experiment of going protein-free for a day or two, which is easy to do by eating vegetables, fruit, baked goods, and then trying a high-protein meal like a hamburger. If the protein load makes a difference, then the patient might adjust his diet to take this into account. In most cases, like yours, they can't tell the difference. Then I tell the patient to eat whatever he wants.

Dr. Friedman is a clinical professor at Brown University School of Medicine, medical director of APDA's Rhode Island Information & Referral Center, and author of "Making the Connection between Brain and Behavior: Coping with Parkinson's Disease," Domos Press.

APDA WALKS ACROSS AMERICA TO FIND A CURE

APDA walk-a-thons have been taking place across the country. Undaunted by rain or heat, walkers of all ages (including the young Bostonian, center) and all species (dogs joined in a number of walks) have raised nearly $300,000 for PD research to date. Future walks include Rhode Island, Midwest, Arkansas, Nebraska, New Hampshire and the now-famous Long Island Dog Walk in October.

Check www.apdaparkinson.org, events page for details and join in by attending and supporting an upcoming walk.


Pennsyvlania

California - San Diego

Nevada


Massachusetts


Massachusetts


Minnesota

California - Los Angeles

New York


Arizona

EDUCATIONAL MATERIAL AND PATIENT SUPPORT RESOURCES

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 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 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 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. 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? **(NEW)**

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

WEBSITES

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

DVD

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

AVAILABLE for DOWNLOAD at www.apdaparkinson.org

- Be Independent: Equipment and Suggestions for Daily Living (Booklet)
- Dr. Andrew Weil's Recommendations for Healthy Aging (Supplement 21)

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