

The American Parkinson Disease Association

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by The American Parkinson
Disease Association, Inc.

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MOTOR FLUCTUATIONS

By Lawrence I. Golbe, MD
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UMDNJ - Robert Wood Johnson Medical School, New Brunswick, NJ

Nearly all persons with Parkinson's disease (PD) eventually develop motor fluctuations, changes in the effect of PD medication, usually levodopa/carbidopa (LD/CD or Sinemet®), over the few hours between doses. This can interfere with work schedules, outings or social events.

The time when the medication is working is called "on" and the opposite is "off." Many people with PD experience involuntary movements (dyskinesias) or hallucinations during the "on" state. This usually is a sign of excessive medication action, not a sign of the "off" state. The reason for the fluctuations is that the brain of people with PD over a period of years slowly loses its ability to store levodopa between doses and must rely on whatever drug has been supplied within the previous couple of hours. About half of people with PD experience fluctuations by the five-year point in their illness regardless of how long they have been receiving medication. In most people with fluctuations, the benefit of a dose of LD/CD lasts 2 to 4 hours and then wears off slowly over a period of an hour. The next dose may take an average of 30 minutes to start working.

There are several possible solutions to this problem:

1 Push the LD/CD doses closer together, creating one additional dose per day.

Advantage: It does not add another item to the medicine chest.

Disadvantage: Does impose the burden of remembering more dose times per day.

2 Add entacapone (Comtan®) to whichever LD/CD doses are likely to wear off too soon, up to six per day. This drug slows the body's ability to excrete LD/CD.

Advantage: Can be tailored to the individual's wearing-off pattern.

Disadvantages: Gastrointestinal side effects such as abdominal pain, gas or diarrhea in some patients.

An alternative drug with the same basic action is tolcapone (Tasmar®), which is taken one to three times a day, not necessarily at the same dosing times as LD/CD. It works better than entacapone but can cause liver damage in very rare cases and requires blood tests as a precaution.

3 Add or increase the dosage of a dopamine receptor agonist such as pramipexole (Mirapex®) or ropinirole (Requip®). Older drugs in this class are the now infrequently used pergolide (Permax®), and the almost no-longer-used bromocriptine (Parlodel®).

Advantages: These drugs not only help fluctuations, but also have their own antiparkinson effects to add to those of LD/CD. They are less likely to cause dyskinesias than adding LD/CD.

Disadvantages: The agonists are expensive, they are more likely to cause hallucinations in elderly or demented patients

LECTURE IN HONOR OF ROGER DUVOISIN, MD

UMDNJ - Robert Wood Johnson Medical School has announced the establishment of an endowed lecture in honor of Roger C. Duvoisin, MD, the first chair of the School's Department of Neurology and an expert in Parkinson's disease and other movement disorders.

As chair of the Department, Dr. Duvoisin created one of the nation's best and largest movement disorders centers, which was designated a Center of Advanced Research of the American Parkinson Disease Association (APDA). Dr. Duvoisin also served as chair of the APDA's Scientific Advisory Board and received the first APDA Contursi award.

Each year an expert in movement disorders will be chosen as the Roger C. Duvoisin Visiting Professor by a committee of the Neurology Department Movement Disorders faculty and asked to lecture on a relevant topic in movement disorders. The first lecture will be in November 2006.

The first recipient of the visiting professorship will be G. Frederick Wooten, MD, the Mary Anderson Harrison Professor and chair of Neurology at the University of Virginia (UVA) in Charlottesville. Dr. Wooten was chosen because his contributions to Parkinson's disease and other movement disorders closely parallel Dr. Duvoisin's.

Dr. Wooten succeeded Dr. Duvoisin as chair of the Scientific Advisory Board of the APDA, and leads the Movement Disorders Center at UVA, also a Center for Advanced Research of the APDA.

The endowed lecture, established through the Foundation of the University of Medicine and Dentistry of New Jersey, is supported by a permanently restricted gift of \$100,000 raised through donations from Dr. Duvoisin's family, colleagues, friends and patients. ■

P R E S I D E N T ' S M E S S A G E



Dear Reader,

This is an exciting time of the year for APDA; it is when we make our contribution to research. In our next issue, we will report to you the institutions and the scientists whose work has been found promising by our Scientific Advisory Board in our quest toward finding the cure for Parkinson's disease. This year more than \$3 million will be allocated, bringing APDA's total contribution to research over the \$30 million mark.

How we achieve this is quite amazing.

APDA does not receive any government or public funds. With limited exception, our revenue comes from individual donations in the form of responses to mailings, memorials, celebration gifts and bequests. Yes, occasionally these gifts can be quite large, especially by people who remember APDA in their wills, but by and large, it is the culmination of thousands of smaller donations from around the country that add up and make it possible for APDA to support the research programs in institutions like UCLA, the University of Virginia, and the Robert Wood Johnson Medical School.

As technology grows and people find it easier to make donations using their credit cards, the computer and Internet have become responsible for more individuals' donations. Via our Web site, www.apdaparkinson.org, a donation may be made with complete security with just three mouse clicks.

But direct mail remains our largest source of support, and as a result, all manner of letters come to my desk. Some people ask to be added to our mailing list and some want to be removed; some people don't want to receive gifts, while others ask if they can obtain more. Some people write to compliment us on our work or comment on a story in the newsletter, and some have suggestions for future stories. I answer every one possible (if they have a return address or telephone number), because we at APDA truly believe that we are here to serve our contributors as well as patients and caregivers and healthcare providers.

And, to publicly answer a common question, no, we do not lose money on gift mailings. One of our most successful mailings costs a little more than \$1 to send, and the average contribution from it is \$25, equating to an additional \$50,000 dollars for research — or one research grant — the grant that may provide the data that does find the cure.

We ask for your patience.

So, please enjoy our gifts to you. If you don't like them, please remember that maybe there are many people who do, and they may be a key to eradicating this awful disease.

Sincerely,

A handwritten signature in dark ink, appearing to read 'Vincent N. Gattullo'. The signature is fluid and cursive, with a large loop at the end.

Vincent N. Gattullo
President

Alternative Therapies & Parkinson's Disease

What does "alternative medicine" really mean?

"Alternative" is a term that implies a non-Western medicinal approach. It often refers to Eastern (traditional Chinese, Japanese, Indian "Ayurvedic") methods of evaluation and treating physical conditions. Many therapies can fall within this category, but the more common ones include acupuncture, herbal therapies, homeopathy, manual therapies (massage, Reiki) spiritual healing, naturopathy, mind-body exercises (yoga, tai chi) and vitamin/enzyme supplements. The term "integrative," "holistic" or "complementary" are preferred instead of "alternative" because these imply an addition or combination of these therapies with established Western medicine approaches (dopaminergic drugs, brain surgery, rehabilitative therapies) into a comprehensive program for the individual person with Parkinson's disease (PD).

What herbs are safe to take and are proven to help people with Parkinson's disease?

The herbs *macuna pruriens*, a plant that contains levodopa, can reduce some of the motor symptoms of Parkinson's disease. Other herbs and many other "over-the-counter" supplements such as vitamins, enzymes and amino acids are loosely regulated by the Food and Drug Administration. This means that the quality, purity and content of any of these supplements are dependent upon the manufacturing company. Almost none of these have been properly studied for the treatment of PD. As a consumer, you should contact the manufacturer directly with questions about the purity and safety of the product as well as consult a licensed specialist (i.e. herbalist, nutritionist) for advice before taking any supplements. Some herbs and supplements can interact with prescribed medications or cause unwanted side effects.

Should people with Parkinson's disease take Co-Q10?

Co-Q10 is not a proven treatment for Parkinson's disease at the present time. Co-Q10 is a vitamin-like substance found within the energy source of every living cell (the mitochondria). It has been shown to occur at lower levels in persons with PD.

A recent double-blind study showed persons with PD who took Co-Q10 300 mg 4 times a day (1200 mg total daily dose) scored 44 per cent better on motor scales than the persons who took the placebo pills over 16 months. This was a small study and whether Co-Q10 truly helps reduce motor symptoms or might delay the progression of PD is unknown. Future studies are needed to help to better understand this. It was found to be harmless to the patients who took it in the study.

What vitamins should people take if they have Parkinson's?

There are no proven vitamins that specifically help reduce the motor symptoms of PD. One theory of the cause of Parkinson's proposes an excess of electrically charged particles called free radicals. Antioxidants, such as vitamin C (500-2000mg/day) help to reduce these free radicals, and therefore this is a vitamin to be considered for taking.

Does exercise really make a difference?

Exercise of any kind that does not increase one's risk of falling is always recommended to increase endurance, improve delivery of oxygen to the brain, heart and muscles, increase muscle strength and mass, and improve coordination, balance and flexibility. Exercises such as yoga and tai chi focus on the mind-body connection and improve balances and mobility for persons with Parkinson's disease.

Can creatine help increase strength?

Yes, creatine is an over-the-counter powder like substance that many athletes take because it helps supply phosphorus to muscle cells so they can make more ATP, the main energy source for all cells. Recommended doses are 1 teaspoon per day mixed with a liquid. People who take creatine feel stronger and often notice an increase in muscle bulk. There are also some medical studies reporting improved thinking and memory in persons who took creatine daily. It is not too expensive, costing only about \$5-10 for a month's supply. Check with your treating physician before taking it to be sure it is safe, especially if you have kidney problems.

What holistic therapies could be tried and where could a knowledgeable doctor be found?

It is important to try therapies that fit your personality, schedule and budget and are readily available. You will need to spend some time and effort to educate yourself about a particular therapy before deciding whether it may help you. You will need to find a licensed specialist for the particular therapy you are considering. Some doctors who are more oriented toward holistic therapies include doctors of oriental medicine (D.O.M.), doctors of osteopathy (D.O.), naturopaths, homeopaths, licensed acupuncturists and herbalists. ■

Adapted from an article by Jill Mariama-Lyons, M.D. published in the Spring - Summer 2005 Issue of the Cedar-Sinai Medical Center APDA I&R Center Newsletter.



Questions & Answers

Enrico Fazzini, DO, PhD

*Assoc. Prof. Neurology, New York University, New York, N.Y.,
University of Nevada, Las Vegas, NV,
N.Y. Institute of Technology, Old Westbury, N.Y.*

Q: My husband is sleepy all day and getting slower. The slowness comes in the late morning and then again after lunch. His doctor told him to take his medications four times a day but he only takes them three times a day and sometimes he forgets to take the third dose. Why is he doing poorly?

A: In order to treat Parkinson's disease and to be able to predict when the medications will work at their best, it is absolutely imperative that you wake up and go to sleep at the same time, eat your meals at the same time, keep the lunch protein low and take your medications at the same time every single day. For example, wake up at 7 am, take your medications, eat a light breakfast at 7:30 am, take your medications at 11 am, eat lunch (minimal protein — chicken, beef, fish, turkey, ham) at noon, take your medications at 3 pm, eat dinner at 5-5:30 pm and then take your medications at 7 pm and go to sleep at 10:30/11 pm. EVERY DAY. Once this is done, your doctor can make effective adjustments in the medications.

Q: I heard about new discoveries in genetics regarding Parkinson's disease. Is Parkinson's disease genetic?

A: Most patients with Parkinson's disease do NOT have an identifiable genetic or environmental cause which is known. However, almost half of the patients with young onset disease (onset below the age of 40) and at least half of the patients with a strongly positive family history do have gene defects that have been isolated. Some of the young onset gene defects go under the names Parkin, alpha synuclein and PINK-1. These defects have to do with the transport and release of dopamine inside the cell that makes dopamine and the sensitivity of those cells to poisoning. The gene that has been isolated in elderly onset family history positive patients is LRRK2, which works as a facilitator of chemical reactions in the dopamine neuronal system. In general if you have a parent and a sibling with Parkinson's disease, your chances of getting it are about 25 per cent. If only one parent has PD, your risk of getting PD is only about 5 per cent. The risk, in the general population of having PD is about 0.3 per cent.

Q: My mother has tried to avoid starting L-Dopa because she heard it will only work for a short period of time. She wants to take it only when she needs it but she has had PD for over 11 years and she is getting to the point where she can barely take care of herself. Should she take it now?

A: It is the duration of disease (the length of time that one has PD) and NOT the duration of therapy with L-Dopa which leads to the inability of L-Dopa to work. It is true that you should use the minimal amount of L-Dopa that is needed to have most of it supplied as extended-release L-Dopa with either entacapone or selegiline and you should take as much dopamine agonist (pergolide, ropinerole or pramipexole) as can be tolerated. Immediate-release L-Dopa does not work as smoothly after three to five years as it does when the diagnosis of PD is first made, but it does continue to work and if you wait too long to start it, it may never work smoothly at all. I believe in getting a patient as good as possible once treatment is initiated and then doing everything possible to keep the patient symptoms from progressing. ■



F.Y.I. is a guide to the efforts and successes of the hundreds of volunteers and staff who work daily to help ease the burden and find a cure and for millions of persons with Parkinson's and their caregivers across the United States.

FYI EDITOR: K.G. Whitford

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MARIE-FRANÇOISE CHESSELET, MD, PH.D **SCIENTIFIC ADVISORY BOARD MEMBER**

At UCLA's David Geffen School of Medicine it is Dr. Marie-Françoise Chesselet who brings Parkinson's disease research together. Dr. Chesselet, who was born and educated in France, is chair of the school's department of neurobiology, and directs APDA's Advanced Center for Parkinson's Disease Research. In addition, she directs two centers supported by the National Institutes of Health (NIH) - the UCLA Morris K. Udall Center for Excellence for Parkinson's Disease Research (supported by the National Institute for Neurological Disorders and Stroke), and the Center for Gene Environment Studies in Parkinson's Disease (supported by the National Institute for Environmental Health Sciences).

After earning her MD and PhD degrees from the University of Paris VI, and completing an internship at the Hospital de l'Hotel Dieu in Paris, Dr. Chesselet obtained a position at the College de France in Paris and subsequently went to the Massachusetts Institute of Technology and the NIH as a visiting scientist. A decade ago she left her faculty position at the University of Pennsylvania and moved west to accept the position of Charles H. Markham Professor of Neurology at UCLA.

Dr. Chesselet, who is the author of more than 100 publications and recipient of numerous honors, is particularly interested in the molecular mechanisms of neurodegenerative disease. Over the years, she has used



Dr. Marie-Françoise Chesselet directs APDA's Advanced Center for Research at UCLA Medical Center, Los Angeles.

wide ranges of techniques to study the functional anatomy of the basal ganglia, their development, and their response to a variety of brain lesions including the cell loss that occurs in Parkinson's disease.

Currently her lab uses mouse models of Parkinson's disease to study the progression of the disease in mammals and develops tests that can be used to evaluate new therapies. She has already discovered several drugs that improve the behavior of mouse models of Huntington's disease and hopes to use a similar approach to develop treatments for Parkinson's.

As director of the Parkinson's research centers at UCLA, she fosters collaboration among all the parties in bringing research "from the bench to the bedside." These include geneticists and epidemiologists who are identifying new risk factors, molecular biologists and neurobiologists working on new drugs, engineers and neurobiologists improving surgical approaches, and the private sector and neurobiologists striving to develop stem cell therapies.

It is a good thing that Dr. Chesselet enjoys travel because she does it extensively to promote the exchange of ideas among Parkinson's disease researchers. She is an avid reader and arts lover. She and her husband, Terry Reisine, take great pride in their 18-year-old son David's photography talent, and his arts major studies at the University of California in Santa Cruz. ■

WORLD PARKINSON DISEASE ASSOCIATION ELECTS DR. PAUL MAESTRONE PRESIDENT



APDA director of scientific and medical affairs Dr. Paul Maestrone, second from left, with members of the World Parkinson Disease Association after his election as president in Washington, DC.

The World Parkinson Disease Association (WPDA) elected Paul Maestrone, DVM, to be its president at its meeting in Washington, DC, Feb. 22. Other officers are Gianni Pezzoli (Italy), scientific coordinator; Joel Miele (U.S.), vice president;

Andre Hovine (France), treasurer; and Sam Grossman (Brazil), legal advisor.

Elizabeth Braun (U.S.), and Joel Gerstel (U.S.) were elected secretary and vice president for North America, respectively.

WPDA is a coalition of 26 countries committed to improve the quality of life of Parkinson's patients worldwide through education. Among its goals are to broaden public awareness of the disease, establish guidelines for a "continuum of educational program" for patients, encourage the standardization of diagnostic procedures and medical and surgical therapies, and support research. It is based in Milan, Italy.

Dr. Maestrone, who is APDA's director of scientific and medical affairs, was a principal in founding the WPDA in 1998 and has served as its general manager since. ■

APDA IN WASHINGTON, DC

It wasn't quite cherry blossom time in the nation's capital, but one week after the largest recorded snowfall in the East, participants of the week-long string of Parkinson's-related events, were happy with the February sunshine.

APDA was represented at the Parkinson's Action Network Summit (Feb. 19-21), the World Parkinson Disease Association meeting (Feb. 22) and the World Parkinson's Congress (Feb. 22-26). ■



Joel Gerstel and the late Sen. Morris Udall's daughter had a photo op during the PAN Summit.



Associate director for scientific and medical affairs, Michele Popadyneec shares information with a visitor to the APDA booth at the World Parkinson's Congress in Washington, DC.



APDA executive director Joel Gerstel shares a lighter moment with the heads of other Parkinson's disease organizations at the Parkinson's Action Network (PAN) Summit in Washington, DC. From the left are PAN executive director Amy Comstock, Michael J. Fox Foundation executive director Debbie Brooks, and Parkinson's Disease Foundation executive director Robbin Elliott.

In the Northeast

Look out Montpelier City Hall! On June 3, APDA will take to rocking the day away, raising funds for PD research in 100 rocking chairs to be placed on the Statehouse lawn. Based on the premise that few people with PD can run a marathon or ride a bike, the **Vermont** Chapter invites participants to rock for a cure. Bruce Talbot from the Vermont Chapter says there will be “mini” satellite Rock-A-Thons at locations throughout the state. Information is available by calling 802-827-9950 or at parkinsonsvt@surfglobal.net.

The **Massachusetts** Chapter was among 30 health-related organizations to sponsor “Making Health Connections,” a first-of-its-kind forum addressing how chemicals in the environment may be linked with diseases and disorders. Organizers called for legislation to reduce toxic chemicals in the environment to protect public health.

In the Midwest

Congratulations to APDA’s new **Wisconsin** Chapter and I&R Center. Coordinator Jessica Hahn reports its first walk-a-thon raised more than \$13,000 and reaped newspaper and television coverage in Madison as well.

In the East

There’s not much skiing going on in

Pittsburgh in June, but APDA will be walking on the 3rd at the Boyce Park Ski Lodge in Monroeville. The annual walk-a-thon will include a buffet lunch for registered entrants with a pre-luncheon talk by Dr. Susan Baser, the I&R Center director. If sailing sounds even more appealing, the eighth annual Three Rivers Cruise and Seminar is scheduled for Sept. 13. It’s a four-hour cruise that includes PD updates, Q&As, and a shipboard buffet lunch. Reservations for both may be made by calling 412-441-4100.

In the South

Vince Gill, one of country music’s finest singer-songwriters, performed to a sellout crowd at the Parkinsons Nashville, benefiting APDA’s **Middle Tennessee** Chapter in January. This was the second event of its kind with an artist reception in the Country Music Hall of Fame Museum rotunda, with an auction of a signed Gibson Les Paul guitar. Chapter president Fabio Fallico hailed the event for creating public awareness as well as raising funds.

In the Southwest

Dallas is gearing up for its seventh annual Parkinson’s golf classic. The all-day event, which includes not just golf but also a silent auction, reception and educational fair, and Mexican buffet at the Brookhaven Country Club, is one of the **Northeast Texas** Chapter’s most popular events.

More information is available at 214-378-2732.

In the West

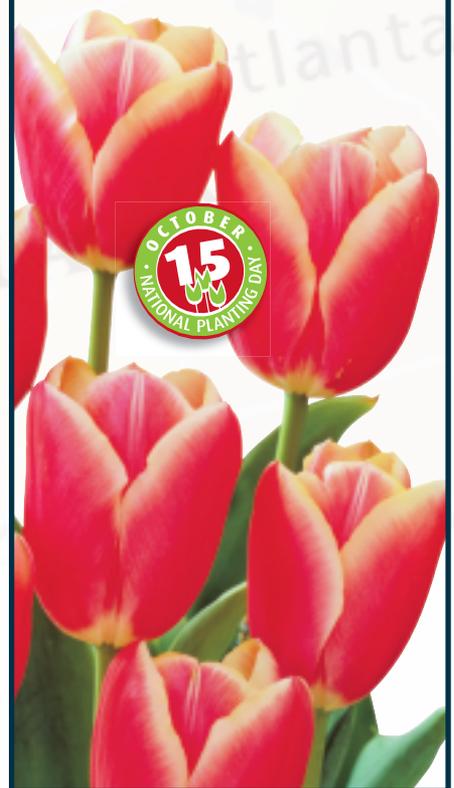
The rain wasn’t going to ruin their parade in **California!** Last month the Greater Los Angeles Chapter had a most successful walk, despite four days of torrential rain. ■

Flower Power for Parkinson’s

40% donation to PD research

Help APDA in the fight against Parkinson’s disease. Make a visible statement and a **40% donation** to Parkinson’s research at the same time.

See insert for details.



APDA WELCOMES FIVE NEW COORDINATORS

There will be at least five new faces at this year's coordinators' annual meeting in Philadelphia in July.

APDA's newest I&R Center at Banner Good Samaritan Hospital in Phoenix is being co-directed by movement disorder specialists Drs. Johan Samant and Padma Mahant. **Thomas Viviano**, who has a degree in biological sciences and secondary education, is the coordinator. In addition, Tom has been a pharmaceutical representative and executive director of a medically oriented not-for-profit organization.

The Stanford, Calif. Center happily welcomed **Martha Gardner, RN, BSN**, after more than a year without a coordinator. Martha is a healthcare professional with broad interests and background, most recently providing patient care in an intermediate ICU. She also has experience in patient assessment, teaching and communications.

Kristine Twomey, RN, BSN is replacing Cheryl Thelen in Neenah, Wis. Kristine's experience includes performing telephone triage with neurological and neurosurgical patients for a neuroscience group, patient assessment and patient and family education.

In St. Louis, where Susan Levin was coordinator for more than 20 years, **Jan Meyer** is beginning her tenure. Jan, in addition to her people and organizational skills, brings years of experience in project development, public relations and creative programs.

While not really new to APDA, **Kathleen Pear, LGSW**, is in a new role as interim coordinator in Baltimore. Kathy is a clinical social worker with emphasis on providing services to clients and their families. ■

PARKINSON'S AWARENESS ACTIVITIES

APDA chapters, centers and support groups across the United States did their part in making April 2006 a most successful Parkinson's Awareness Month. Across the country governors, mayors and local officials presented proclamations to heighten awareness of the disease and recognize the efforts of all those who are working to ease the burden and find the cure.

In Mississippi, Gov. Haley Barbour issued a proclamation, as did Mayor Johnny Dupree in Hattiesburg, Mayor Roger Herrin in Purvis, and Mayor Nancy Chambers in Forest. Coordinator Brenda Allred also reported statewide news stories including a feature article in the Vicksburg Post.

Tennessee mayors Keith McDonald of Bartlett, Terry Jones of Millington and Dr.

son's Disease Awareness Month.

Gov. Sonny Perdue had a private meeting with Georgia Chapter president Carol Palmer, I&R Center coordinator Mary Louise Weeks, and Glen Rapp, representing early



Georgia's governor signs proclamation.

onset patients for his signing of a proclamation.

Maine coordinator Lillian Scenna not only received word from the president of the state senate, Beth Edmonds, that a proclamation was being signed, but also was invited to be present when the Parkinson's Joint House and Senate Resolution was passed.

In Texas, Mayor Ron Silva issued a proclamation from the city of College Station, and Dallas Mayor Laura Miller delivered her proclamation to Dallas Chapter President Beth Moody and Fred Greene, APDA's third vice president.

Mayor Kennedy O'Brien added recognition of APDA's contributions to the residents of Sayreville, N.J. in his proclamation. ■



Shannon Massey receives proclamation from Mayor McDonald.

Willie Herenton of Memphis all proclaimed April as Parkin-

Parkinson's Disease In Women

By Susan M. Rubin, MD

Until recently little has been written regarding the effect that gender has on the development and management of Parkinson's disease (PD). Current research has focused mainly on the impact that sex hormones have on the development of Parkinson's disease. Less has been written on the impact that PD has on menstruation, pregnancy and menopause. This article will review the most recent information on both the effect that Parkinson's disease has on women and the impact that gender has on PD.

While PD is usually thought of as a disease of the elderly, approximately 3 to 5 per cent of women diagnosed with the disorder are under the age of 50. A large number of these women are still experiencing regular menstrual cycles. Studies that have reviewed the effect of hormone fluctuations and menstruation on PD have noted an impact of the menstrual cycle on disease control. During menstruation women described increased Parkinson symptoms, decreased medication responsiveness and increased "off" time. They also complain of increased fatigue, cramps and heavier menstrual flow. This can lead to occasional humiliating self-care issues due to worsening dexterity. Pre-menstrual symptoms of depression, bloating, weight gain and breast tenderness also appear to increase in intensity in women who note a variation in their symptom control with menstruation. Usually these symptoms improve after menstruation, but will reoccur with each cycle. A small sample of women in the studies used birth control pills. They reported that they had less intense

fluctuations in their symptom control, but more research needs to be done before recommendations can be made. However, it is important to recognize that these fluctuations occur so that women can be prepared for the changes in control. The use of regular exercise and relaxation techniques can help decrease symptoms and improve coping abilities.

There have been only a limited number of pregnancies to women with PD reported. The data have been divided into the impact that pregnancy has on PD and the effect that PD has on pregnancy. There is an increase in both motor and non-motor symptoms during pregnancy although it is rarely significant enough to impact the women's overall level of functioning. Non-motor symptoms (such as fatigue, constipation and depression) seem to improve after delivery but any progression of motor symptoms rigidity, slowness of movement and tremor usually persists. While data have shown that increasing length of estrogen exposure (the amount of time from puberty to menopause) decreases the risk of developing PD, increasing amount of time spent pregnant seems to increase the risk of developing Parkinson's disease. This seems contradictory but may be due to differences in the effect that estriol (the pregnancy form of estrogen) and estradiol (the menstrual form of es-

trogen) have on the disease.

The main concern of pregnant women with PD is the risk of birth defects from antiparkinson's medications. The dopamine agonists, bromocriptine and pergolide are considered relatively safe during pregnancy but make it impossible to breast feed because they block milk production.

The remainder of the antiparkinson's medications carries a category C rating, meaning that animal studies suggest some risk, but human studies are not available or have not confirmed that risk. The data on levodopa either with or without carbidopa suggest some risk in animal studies, but there were no reported birth defects in newborns in the small number of pregnancies reviewed. Amantadine is the only antiparkinson's medication that has resulted in heart malformations in babies with first trimester exposure. There were no reports of major malformations with the use of Selegiline (Eldepryl®) and there are no data available so far on the COMT inhibitors.

Women with PD do not have trouble with fertility, but can have changes in self-image that lead to social avoidance and difficulty with sexual intimacy. This can lead to decreased pregnancy rates and sexual dysfunction. Women who do become pregnant must then face the challenge of caring for a child postpartum. The American Parkinson Disease Association offers resources and helpful staff to provide information and support regarding pregnancy and parenting issues related to PD. Establishing a support system and planning are critical to being an effective



continued on page 10

tive parent, especially if you have a progressive disease.

It has been noted that women are more likely to develop PD later than men and usually when they are postmenopausal. Basic science research with rats has shown that there is an increase in the slow decline in dopamine-producing cells coincident with menopause. Use of hormone replacement in rats that have had their ovaries removed seems to reverse that increase. However, studies in women have had contradictory results showing only partial or no benefit from hormone replacement, since the animal studies have shown a difference in benefit based on the timing of the hormone supplementation. The rats who received



hormone supplements within 10 days of having their ovaries removed had no increase in the loss of dopamine producing cells, while rats that did not receive estrogen until 30 days later did lose cells more rapidly. They did not see any benefit from the supplements in the rats who received them later.

The few studies that have compared the impact of hormone replacement therapy on disease progression have been mildly positive. Women on hormone replacement reported more “on” time and lower UPDRS scores than non-estrogen users. Unfortunately the number of women studied is too low to support the use of hormone replacement at this time. The benefits still need to be weighed against

the risks recently reported in the Women's Health Initiative study.

In conclusion, we are beginning to understand the impact of sex hormones on the development and progression of PD. Recent studies suggest that there is an inverse relationship between lifetime estrogen exposure and the risk of developing PD. It has also been shown that fluctuations in hormone levels will result in changes in disease control and result in the need for changes in symptom management during menstruation, pregnancy and menopause. Hopefully, we will gain further understanding which will lead to new treatment options for women with PD.

For more information contact APDA Young Onset Parkinson's Disease Center at (847) 657-5787. ■

This article originally appeared in the Winter 2005 Issue of the APDA Young Parkinson's Newsletter.

Motor Fluctuations continued from page 1

than LD/CD, and they can cause sleep attacks and compulsive behavior.

4 Add selegiline (Eldepryl®), which, like entacapone and tolcapone, slows the excretion of LD/CD and may have other effects.

Advantages: It is usually used once or at most twice per day. It may have a long-term protective action in PD.

Disadvantages: Modest effect on fluctuations; it may cause or aggravate dyskinesias or hallucinations.

5 Substitute a longer-acting form of LD/CD (LD/CD ER or Sinemet CR®). It turns out that this does not work, as well as logic would suggest, and it can prolong the dyskinesias or hallucinations that occur during the

“on” state. Also this form takes longer to start acting, a problem if one is “off” at dosing time. The elderly may not absorb this form of LD well — especially in its generic form.

6 Use injectable apomorphine (Apokyn®). This drug, a dopamine agonist like pramipexole and ropinirole, must be injected under the skin using a semi-automatic, nearly painless injector device.

Advantages: Starts to act in 15 minutes rather than the 30 typically required by other medications.

Disadvantages: Cost; works for only one hour; you must take an oral medication every day to prevent the vomiting that apomorphine causes during the first few months of use.

7 Dietary protein manipulation: Taking LD/CD with protein-containing food will prolong its action, possibly preventing that dose from wearing off. If you are “off” at dosing time, taking LD/CD on an empty stomach will speed the drug's onset of action.

New medications are being developed to address motor fluctuations. These include drugs in patch form and oral medications that act on the brain in ways different from existing drugs.

It is important to recognize fluctuations and to report them to your neurologist so that your lifestyle and activities do not have to suffer unnecessarily.

Fluctuations are one of the most treatable of PD's complications. ■

Foot Cramps in Parkinson's Disease

aching and cramping of the feet are common complaints, often occurring after injury (sprains and strains), excessive exercise or in association with arthritis or poor circulation in the legs. In Parkinson's disease (PD), cramping of the feet is also very common, but the cause is central rather than peripheral. Foot cramping is just one of several focal dystonias — abnormal, sustained tightening of muscles — that appear to be due to neurochemical abnormalities in the basal ganglia, the part of the brain involved in PD.



Patients show a particular type of cramping characterized by downward clenching of the toes or inward turning of the foot. Cramping can occur throughout the day or night, and can be especially annoying when interfering with sleep. Foot cramping is more common among those individuals in which PD affects just one side of the body. Dystonias are often mistaken for other causes of muscle cramping. Patients with dystonias may be entirely unaware of any Parkinsonism; indeed, muscle cramping can precede the onset of Parkinsonian symptoms by years.

There are no laboratory tests that can distinguish dystonia from other causes of cramping, although a thorough neurologic examination and specialized tests should pinpoint the cause. Some dystonic features — such as blepharospasm (involuntary closing of the eyelids) or torticollis (involuntary turning of the neck) — are common in the general population. In the PD patient receiving levodopa/carbidopa (Sinemet®), focal dystonias may be caused by either too much of the drug or too little. Patients may experience dystonia when peak drug levels are attained one or two hours

after administration, or hours later when drug effects wear off.

Changing the dose or dosage schedule of Sinemet, or using the sustained-release formulation (Sinemet CR®)

may help. The monoamine oxidase B inhibitor selegiline (Eldepryl®) may also help. A bedtime dose of Sinemet CR, pergolide (Permax®), or bromocriptine (Parlodel®) may prevent foot dystonia during early-morning hours. Some patients respond to anticholinergics such as trihexyphenidyl (Artane®), muscle relaxants such as cyclobenzaprine (Flexeril®) and baclofen (Lioresal®) and the anticonvulsant clonazepam (Klonopin®).

Another treatment giving excellent relief is botulinum toxin (Botox®). Injected into the dystonic or cramping muscle, botulinum toxin reduces the intensity of the spasms, and the effects may last months after injection. The toxin is also used for Parkinsonian tremors, benign essential tremor, and a number of dystonias not always associated with PD. These include blepharospasm, torticollis, dysphonia (cramping of the vocal cords), strabismus (wandering eye), stuttering, and large-muscle spasms associated with conditions such as stroke, head trauma, and multiple sclerosis.

A careful evaluation of the time relationship between foot cramping and the levodopa dosage schedule should help the physician decide how best to treat this uncomfortable manifestation of PD. Modifying the levodopa regimen or adding other anti-PD agents can alter signals from the brain that trigger the contraction, or the muscle itself can be “paralyzed” with botulinum toxin. ■

Abstracted from an article published in the APDA Summer 2005 Nashville Chapter Newsletter.

PD & THE NEBRASKA TELEHEALTH NETWORK

*By Lisa Brovold, Coordinator
APDA I&R Center, Omaha, NE*

The American Parkinson Disease Association (APDA) Information and Referral Center in Omaha, Nebraska is exploring a new frontier in Parkinson's education. On January 27, 2006, the APDA Information and Referral Center hosted its first teleconference which was broadcast live to ten different sites via the Nebraska Statewide Telehealth Network. The sites were Atkinson, Columbus, Fairbury, Grand Island, Kearney, Lincoln, Norfolk, North Platte, Omaha and York. All participating locations were able to hear and see Dr. John Bertoni, the speaker and Medical Director of the APDA Center, as well as interact with questions and answers. While there were a few problems to be worked out, overall the teleconference was a success and a total of 149 people participated in this event.

The Telehealth Network's significance is that it will allow the APDA Information and Referral (I & R) Center located in Omaha to go to the rural and remote areas of Nebraska so they can participate in much needed Parkinson's education and training. It will enable to utilize expert medical professionals in the local area, which, in turn, will benefit all of Nebraska via the Telehealth Network. It will allow those patients who are unable to travel long distances to receive

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Information on Parkinson's Disease

Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling the toll-free number 1-800-223-2732 or Faxing to 1-718-981-4399.

EDUCATIONAL BOOKLETS

1. **Basic Information about Parkinson's Disease**
4-page brochure (English, Chinese, Spanish)
2. **Parkinson's Disease Handbook**
Symptoms, causes, treatment; 40-page booklet (English, German, Italian, Portuguese, Spanish, Russian)
3. **PD "n" Me — Coping with Parkinson's disease;**
70-page booklet (English)
4. **Be Active — A suggested exercise program for people with Parkinson's disease;** 25-page booklet (English, German, Italian)
5. **Be Independent — Equipment and suggestions for daily living activities;** 32-page booklet (English, German, Italian, Spanish)
6. **Speaking Effectively — Speech and swallowing problems in Parkinson's disease,** 34-page booklet (English, Japanese)
7. **Good Nutrition**
20-page booklet (English), new edition
8. **Young Parkinson's Handbook**
78-page booklet (English)
9. **How to Start a Parkinson's Disease Support Group**
24-page booklet (English, Italian)
10. **Aquatic Exercise for Parkinson's Disease**
20-page booklet for patients and their families (English)
11. **Next Step After your Diagnosis — Finding Information and Support**
23-page booklet (English)
12. **My Mommy Has PD... But It's Okay!**
20-page booklet for young children.

EDUCATIONAL SUPPLEMENTS

Caring for the Caregiver: Body, Mind and Spirit; The Family Unit; The Fine Art of "Recreating & Socialization" with PD; Medical Management of PD; Vision Problems and PD; Mirapex® in the Treatment of PD; Fatigue in Parkinson's Disease, and others.

DVD

Managing Parkinson's — Straight Talk and Honest Hope.

Created by the Washington State Chapter of APDA especially for newly diagnosed Parkinson's patients and their loved ones. Leading experts explain what PD is and how it is treated, how to deal with symptoms of the disease and some of the medications' side-effects and how to keep a positive outlook in dealing with it.

APDA WORLDWIDE WEB SITE

www.apdaparkinson.org for PD I&R Centers, Chapters, Support Groups, Education and Information Material, Meeting Dates, Publications, Medical Abstracts, Clinical Trials, etc.

WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

www.wpda.org/ A weekly-updated source of world news.

PD & THE NEBRASKA TELEHEALTH NETWORK

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quality information in their own home town.

The cost to provide this quality educational program is minimal. Most of the host locations do not charge a fee as long as their technician does not have to stay for the entire conference and the program is run during regularly scheduled business hours. The support group facilitator at that location greets the attendees and has been trained to assist with the microphone. Since the majority of the speakers are from Omaha or the surrounding area, there is no cost for travel expenses or honoraria.

The Information and Referral Center held three additional teleconferences in April in observation of Parkinson's Awareness Month. Dr. Kenneth Follett from the University of Nebraska Medical Center, spoke on "Deep Brain Stimulation" on April 6th; four patients and one caregiver presented a First Person Parkinson Perspective panel discussion on April 21st, and Patricia Gill, MS, CCC, lectured on "The Effects of Parkinson's on Speech and Swallowing" on April 28th. ■

Materials concerning the research in the field of Parkinson's disease, and answers to readers' questions are solely for the information of the reader and should not be used for treatment purposes, but rather as a source for discussion with the patient's health provider.