

The American Parkinson Disease Association

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 Disease Association, Inc.

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Some Questions to Ask Your Neurologist About Your PD Treatment

By Lawrence I. Golbe, MD
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 New Brunswick, N.J.

In most neurological practices, including my own, a routine follow-up visit allows only limited time for questions and answers. After my patient tells me about the progress of symptoms since the previous visit — and I ask my own questions, sort out and record the answers, examine the patient and issue recommendations, — the time available for the visit has pretty much run out.

But if my patient arrives with a written list of questions, I can pace the encounter to allow time for them. If I just read the list myself, I can answer them in a logical and relaxed fashion as the visit proceeds.

Now the hard part: What questions do you ask your neurologist? Of course, some questions will be determined by your symptoms and how much information you have gleaned from other sources such as books, reliable Web sites and newsletters from reliable organizations such as the APDA. But here are five questions that many people with Parkinson's disease (PD) might consider asking about their treatment:

1 Am I on enough medication? PD medication should not be started until the symptoms start to interfere with daily activities, or slow the activities to the point that compensating for the slowness amounts to a burden. It is logical, then, that the treatment's dosage should be adequate to lift this burden or interference. Many neurologists however, in their desire to avoid side effects, under-treat PD.

As the illness approaches its advanced stages, attempts to increase the medication dosages to an effective level result in unacceptable medication side effects, and this causes many neurologists to give less than effective dosages.

Many of these drug side effects such as dyskinesias and hallucinations can be dealt with in other ways. In many cases, in fact, the patient prefers mild or moderate dyskinesias to "off" periods, and the neurologist should recognize this and tailor the medication dosages accordingly.



ESSENTIAL TREMOR AND PD OFTEN CONFUSED

By Melissa Houser, MD
Scripps Clinic, La Jolla, Calif.

Tremors occur in a variety of illnesses, but two common neurological conditions associated with tremor are Parkinson's disease and essential tremor. Although these two disorders differ in many ways, doctors and patients sometimes confuse them.

Essential tremor may begin quite early, even in childhood, but most people notice it becoming a nuisance in their 50s, and it may worsen with age. The tremor often involves the hands, head and voice.

The hands may shake when performing any simple action. Generally, if the hands are not moving, the tremor is absent (but there are exceptions to this rule).

The cause of essential tremor is unknown, although there is a strong hereditary component — so much so that many doctors use the term “familial tremor.” This tremor disorder is generally considered benign because it is not associated with a progressive neurological illness leading to significant disability.

Many people with severe forms of the tremor find eating or drinking without spillage impossible. They may experience depression, embarrassment and subsequent social isolation. For a person who requires very steady hands to perform a job, or for those in the public eye, the tremor can, indeed, lead to disability.

The good news is that this tremor can be treated. Although there is no “cure” for essential tremor, several medications may help alleviate it. Most physicians usually prescribe one or two drugs to help; a blood pressure drug called propranolol (Inderal®) and/or an antiseizure drug called primidone (Mysoline®).

Some patients take the medication daily, but some may reserve taking the drugs for a certain need, such

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



Dear Reader,

I think it is most appropriate that Parkinson's Awareness Month comes in the spring, because spring is the season of hope.

APDA's original objectives, to heighten the country's awareness of the disease and to raise funds for research, have grown well beyond its founders' greatest aspirations, and today we are proud of our role as the international leader in PD education and awareness.

Through nationwide walk-a-thons and a myriad other special events at which literature is disseminated, educational lectures and symposia, and a library of free publications on all aspects of the disease in English, French, Spanish, Portuguese, Chinese and Italian, APDA is the principal national and international source of information about the disease. Indeed, approximately one quarter of our expenses (50 percent, if you add our Information & Referral Centers) are for educational programs.

In 1994, APDA formalized a working relationship with the Associazione Italiana Parkinsoniani (AIP), a small organization of 3,000 Italians with PD, caregivers, friends and medical professionals. Today AIP has 23 offices across Italy, more than 25,000 members, sponsors annual national conventions for patients and their families, and has recently established a Young Onset Parkinson's Group.

Upon their collaboration, the two organizations established an Electronic International Parkinson's Disease Resource Guide with 13 initial participants, which has grown to become the 25-member World Parkinson Disease Association.

In recent years, as the public learned that some very visible persons in highly respected and responsible positions were persons with Parkinson's, there evolved a greater understanding of the condition and respect for those with it. Add to that insight, new drug therapies, successful surgical interventions, and the growing areas of research, we have reasons to look toward a brighter future.

In this issue you will read about some of the efforts made by volunteers across the country to raise awareness as well as funds for PD research. APDA's individual Chapters and I&R Centers used their collective talents and energies to package fund-raising and educational activities in fun-filled events.

In addition, their leaderships requested formal proclamations from state and local officials to promote awareness. To name a few: George McHugh, president of the Granite State Chapter arranged for New Hampshire Gov. John Lynch to issue and present a “World Parkinson Awareness Day” proclamation last month, and Dianne Johnson, RN, San Antonio, Texas, coordinator, led a bus filled with patients and caregivers to City Hall to receive a proclamation in March. Florida's Suncoast Chapter, led by Ginna Bernard, arranged for endorsements by Gov. Jeb Bush.

New Mexico's chapter president Bob Dunagan and his wife, Charlene, who was diagnosed in 1979, sent 123 solicitations to more than 20 major tribes or pueblos in New Mexico, as well as to New Mexico Gov. Bill Richardson. Among the nations contacted, each with its own governor, were the Navajo, Mescalero Apache and Jicarrilla Apache.

In FYI, you will read a poem written by 9-year-old Bernadette Bianchi from Colorado for her grandmother. It falls into the “out of the mouths of babes” department.

We all wish you a happy spring filled with the hope and promise of more than perfect weather and gardens.

Sincerely,

A handwritten signature in black ink, appearing to read "Vincent N. Gattullo". The signature is written in a cursive style with some loops and flourishes.

Vincent N. Gattullo
President

2 Would a dopamine agonist be better than carbidopa/levodopa (Sinemet®) for me?

In general, patients who are younger than 65 or 70, have no thinking difficulties and are in the early stages of PD do better on “dopamine receptor agonist” drugs such as pergolide (Permax®), pramipexole (Mirapex®) or ropinirole (Requip®) than on carbidopa/levodopa (Sinemet® or Parcopa®). This is because the agonists are less likely to produce involuntary writhing or bobbing movements called dyskinesias. It is true that the agonists are more likely to cause hallucinations and are less effective against the movement symptoms of PD, but these drawbacks are less prevalent in younger patients.

3 Am I on unnecessary treatment for dose-related fluctuations?

About half of all patients with PD of five years' duration develop dose-related fluctuations on Sinemet treatment. This is where the effectiveness of a dose, which is usually twice a day at the onset, starts to wear off before the next dose. There are several ways to deal with this, including:

- Creating a third dose at midday.
- Adding a “COMT inhibitor” such as entacapone (Comtan®) or tolcapone (Tasmar®).
- Adding an “MAO-B inhibitor” such as selegiline (Eldepryl®) or the soon-to-be-released rasagiline.
- Adding amantadine (Symmetrel®).
- Adding a dopamine agonist.
- Using a combination of these.

Note that a PD drug that recently entered the market, Stalevo®, is merely a combination of carbidopa/levodopa (Sinemet) and entacapone (Comtan). It therefore, should be used only in patients who have experienced an unacceptable “wearing-off” effect.

Nevertheless, it is being prescribed (unnecessarily, in my opinion) by many physicians for anyone with PD whose response to levodopa/carbidopa is inadequate, or even as an

initial treatment years before “wearing-off” is likely to occur.

Some of the experts believe that selegiline (Eldepryl®) can slow the long-term loss of dopamine-producing brain cells in addition to whatever effect it has on the immediate symptoms. If your neurologist is in agreement with this minority (but legitimate) view, then there is reason to have that drug as part of any PD regimen.

4 Is some of my difficulty from unrecognized dose-related fluctuations?

This is the opposite of the previous question. Many neurologists fail to ask if the PD symptoms fluctuate over the course of the day in a pattern corresponding to the medication dose times. The patient may just assume that any hour-by-hour fluctuations in medication effect are “normal” and irremediable. If you are having difficulty with some of your activities, ask yourself whether that problem tends to develop toward the end of the interval between PD drug doses and improves about a half-hour after the next dose. If that is the case, one of the anti-fluctuation measures listed above may be for you.

5 Is there any way to prevent the nausea or loss of appetite that my PD medications cause?

About 10 percent of people with PD experience nausea or loss of appetite as a side effect of dopaminergic medications (i.e., carbidopa/levodopa and the agonists). While this side effect usually disappears in a few weeks or months, it can be so severe as to prevent use of the drug. Many neurologists are unaware that there are things that can be done for this. First, if the nausea is caused by carbidopa/levodopa, adding additional carbidopa (which is represented by the “25” in “25/100” pill) can prevent nausea. Levodopa alone causes nausea in nearly everyone, and the carbidopa comes in the tablet to prevent this.

But some people need more carbidopa (I always use the 25/100 combination rather than the 10/100 to reduce the chance of encountering this situation.) Plain carbidopa is marketed as 25 mg tablets called Lodosyn®, so by adding three or four doses per day to accompany the carbidopa/levodopa in such patients usually succeeds in preventing the nausea. The supplemental carbidopa can usually be discontinued in a month or two.

Another option is to prevent the nausea with domperidone (Motilium®), which is given a half hour before each dose of the offending PD medication. It is not available in the US, but can be ordered by mail from Canada. It blocks the action of dopaminergic drugs in the brain's vomiting center but not in its movement center. Anti-nausea drugs available in the U.S. such as prochlorperazine (Compazine®) and metoclopramide (Reglan®) block both areas, which means that they can make the movement abnormalities of PD much worse. The drug trimethobenzamide (Tigan®) is slightly less effective against nausea but also less likely to aggravate PD symptoms. ■



Questions & Answers

Enrico Fazzini, DO, PhD

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

Q: I have had Parkinson's disease for 12 years. I am doing well but with occasional episodes when the room seems to get hot and I become sweaty. At other times when I am standing, I find myself swaying. I am taking Requip 2 mg at 8 am, 1 pm and bedtime and Sinemet 25/100 every three hours while I am awake. Any suggestions?

A: You are having fluctuations in response to your medications with "off" periods characterized by sweating and "on" dyskinesia characterized by swaying. You should increase your Requip so that you take it with every dose of Sinemet, reduce your Sinemet to half and add 1/2 of a Controlled Release Sinemet 50/200 and 1/2 to 1 whole Comtan every dose. This should help.

Q: I am very slow in the morning until five hours after I begin my medication. I am taking Comtan 200 mg and Controlled Release Sinemet 50/200 at 8 am and 2 pm. What should I do?

A: You should add some immediate release Sinemet. There is a new preparation called Parcopa which is an orally dissolving L-Dopa preparation with quick onset of action in 5-10 minutes in most patients.

Q: My neurologist has tried me on Requip and Mirapex. Both of these medications made me very sleepy all day long and did not help me. I am afraid to start Sinemet because I heard it will only work for a few years. What should I do?

A: Immediate release Sinemet only works smoothly for three to five years. The controlled release preparations of L-Dopa and Comtan work smoothly for many more years and can be taken with small amounts of immediate release Sinemet. There has never been demonstrated a deleterious effect on disease progression by taking L-Dopa. That being said, I am a firm believer in the use of dopamine agonists because I feel that these medications are able to keep the areas of the brain that need dopamine healthier for longer periods of time. Furthermore, dopamine agonists should prevent the stress on the neurons which

are trying to make more dopamine. Permax (pergolide) is still a very effective dopamine agonist with little sedation. Although it is true that rarely at high doses patients could develop ergotism, the vast majority of patients in my practice do very well on this dopamine agonist. I would give it a try.

Q: My husband has been doing well with PD for several years but thrashes around the bed during the night sometimes almost hitting me. He does not remember anything when he wakes up. He tells me he had no nightmares. The doctor said not to worry about it. What do you think?

A: During dreaming, people without PD are inhibited from movement by their brain. In patients with PD, this inhibition is lessened so that if a patient dreams of running, he may actually move his legs. If he dreams of using his arms, he may actually move his arms. You could try lowering the last medication dose of the day, but in itself, the thrashing is not a problem except to the partner in bed. ■

F.Y.I. is an informational 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 PWP and their caregivers across the United States.

Joel S. Perlmutter, MD

APDA Scientific Advisory Board Member

Prophets traditionally are not recognized in their own lands, but it would be difficult for Missouri to ignore the accomplishments of its native son, Joel Perlmutter. Born and raised in St. Louis, he left only to earn his undergraduate degree from Princeton University in New Jersey, complete a psychiatry externship at the Menninger Foundation in Kansas, and serve as a visiting research registrar at the Institute of Psychiatry and King's College Hospital in London.

All his other work that has established him as a physician and researcher of national prominence — including being named among America's Top Doctors every year since 2001, and a page full of other awards — has been done at Washington University School of Medicine in St. Louis.

Dr. Perlmutter's dedication to PD research is personally as well as professionally driven. It was he who diagnosed his father and his late uncle, leading to his research commitment to find a cure or slow the progression of the disease.

A diplomate of the American Board of Neurology and Psychiatry and the National Board of Medical Examiners, and member of the Missouri Board of the Healing Arts, Dr. Perlmutter is also the Elliot H. Stein Family Professor of Neurology, professor of radiology and physical therapy and associate professor of

anatomy and neurobiology at Washington University Medical School. He also heads the Department of Neurology's Movement Disorders Section.



Dr. Perlmutter finishing a recent Boston Marathon

Dr. Perlmutter served on the National Institutes of Health's panel to devise a five-to-10-year plan for PD

research at its National Institute of Neurological Disorders and Stroke.

In addition to his place on the APDA Scientific Advisory Board, he serves on the Parkinson Study Group.

With 127 peer-reviewed publications, repeated invited presentations across the country, and as an ad hoc reviewer for 17 professional journals, he is a recognized and respected authority in his field.

An avid runner, occasional marathoner, and rock star (minerals, not music — in fact, he confesses that singing is a lesser talent), Dr. Perlmutter also serves his community by volunteering his time and talents at several eldercare residential facilities.

Of all his accomplishments, however, he is proudest of his family, including his wife, Monica, who is an occupational therapist also on the Washington U. faculty, two daughters, Lauren, 15, and Anna, 12, and a 10-year old son, Nathan. ■



Enter the magical world created by Frank Ballard, puppeteer and Parkinsonian, page 8

Destination Discovery Walks Take Place Across the Country

T.S. Eliot may have said that April is the cruelest month, but for Parkinson's disease research, it is one of the kindest. April is Parkinson's Disease Awareness Month, and many APDA Chapters and support groups schedule their annual walk-a-thons with proceeds dedicated to PD research. Last year that translated into more than half a million dollars.

Texas and Florida led off this year's walks on April 2, with a 5K walk honoring Dr. John Brady in Waxahachie, Texas, and family-fun events by the South Florida Chapter at Delray Beach, and Lake County support group in Leesburg, Fla.

Food was a big draw the following weekend. San Antonio, Texas, began its walk in Eisenhower Park with a free taco breakfast and had a pizza lunch, and the Nashville, Tenn. walk included a barbecue.

The "biggie," of course, was on April 16, when the 11th Parkinson's Unity Walk stepped off in New York City's Central Park. The walk brings together all the organizations working toward a PD cure and attracts more than 8,000 people from around the country. Proceeds are divided among the groups and their research program.

Atlanta, Ga. held its walk on April 16, followed the next day by a mall walk in Reno, Nev.

During April's last weekend, the Iowa Chapter held a walk in Cedar Rapids, the Minnesota Chapter and I&R Center walked around Lake Como in St. Paul, the Brazos Valley Association Chapter had its annual 5K Fun Run in memory of Coach Tom Chandler in Bryan, Tex, and the Arizona Chapter had its walk, as did the Asheville Chapter and support group in North Carolina.

The Long Island (NY) Chapter chose Belmont Lake State Park for its May 7th walk, and San Diego walked in Mission Bay Park on May 14. The Las Vegas Chapter and I&R Center "New York to Paris" walk on May 21 isn't as long as it sounds; it's between the New York Hotel & Casino and the Paris Hotel & Casino. The Pittsburgh Chapter rounds out May with its walk at the Four Seasons Ski Lodge.

The following walks are scheduled through the summer: Nebraska Chapter and Northern Utah support group, June 4; Massachusetts Chapter, June 12; Midwest Chapter, Sept. 10; and Connecticut Chapter, Sept. 18.

Consult the APDA Web site, www.apdaparkinson.org, for contact information on the current events page. ■



Former U.S. Attorney General Janet Reno, third from left, shared her experiences in a national leadership role as well as her life with PD at the Midwest Chapter's Symposium 2005, in Chicago. With her at a reception before her speech are Joel Gerstel, APDA executive president; Marixine Dust, North Central regional representative; Susan Reese, I & R coordinator; Mary Anne Ostrenga, Chapter president; and Dr. Michael Rezak, the Center's medical director.



The APDA Tampa Bay, Fla. team brought the sunshine to the 11th Annual Parkinson's Unity Walk in Central Park. The group came in 10th of 270 teams in donations raised in its first attempt. More than 8,000 people joined to walk and raise funds for PD research. More than \$1 million has been raised to date.



The Greater Los Angeles Chapter celebrated the results of its efforts for World Parkinson Disease Awareness Month. Persons with Parkinson's, physicians and public officials showed off national, state and local proclamations before breaking for cake and desserts at the Chapter meeting.

Master Puppeteer Heads His Own Museum at UConn

Just about everything Frank Ballard does has strings attached.

At 5 years old, Frank knew that the art of puppetry was to be his life's work after his aunt took him to his first puppet show in his native Illinois. What he didn't realize was that he would become an award-winning master puppeteer, establish the nation's first university degree program in puppetry, and have a museum named for him. Nor did he ever expect to become a person with Parkinson's disease.

Frank and his high school sweetheart, wife of 52 years, and devoted assistant Adah Ruth, relocated to Connecticut in 1956 when he joined the University's School of Fine Arts faculty as a teacher and theatre scenic designer. By 1962, he had 12 students enrolled in a formal program that included the study and application in the history, technical aspects, woodcarving, drawing, set design, script writing and presentations of puppet arts. Today the program has 38 students and is under the direction of Bart Roccoberton, Jr., one of Frank's former students, while as professor emeritus of dramatic arts, Frank directs the magical Ballard Institute and Museum of Puppetry (BIMP).

The museum occupies its own building on the university's campus in Storrs, Conn., and offers new exhibits every year from late April to mid-November. BIMP is

totally volunteer-operated and includes docent-led tours, performances, and workshops for families and teachers. This year's exhibit includes puppets, drawings and art from 20 shows Frank produced, including the three that earned the Union International of the Marionette's Award for Excellence in Puppetry. There is also a "hands-on" room for the younger set to experiment with creating their own puppets and

famous artists.

The puppets in this year's exhibit include string, stick, hand, and rod puppets from Frank's 20 productions. Included are drawings, props, scenery and puppets from the 1968 production of "Mikado;" Frank's favorite, "Kismet;" Adah Ruth's favorite, "The Magic Flute;" the 1980 production of the "Ring of the Neiberlon," which was presented at Kennedy Center in Washington, DC, and the last show, "HMS Pinafore," presented in 1989.

At age 75, Frank has faced his PD head-on and continues his museum schedule uninterrupted. He suspects that continual exposure to toxic materials in his life's work is responsible for his disease and has participated in a drug trial at Yale Medical School, and is presently enrolled in another

at the University of Connecticut. He is also considering deep brain stimulation surgery.

But whatever comes, he is dedicated to the fine art of puppetry, which over the years he has heard denigrated and dismissed as not being art at all. "No has any idea of the influence of puppetry," he says, and is quickly joined by Adah Ruth, who says, "Everything stems from puppetry."

The museum is open Friday – Sundays, noon to 5 pm and can be seen at www.bimp.uconn.edu. ■



Frank and Adah Ruth Ballard introduce some of their friends from his 1968 production of the "Mikado," one of exhibits in this year's Ballard Institute and Museum of Puppetry at the University of Connecticut.

producing a show on a puppet stage.

In addition the museum's collection includes thousands of marionettes, rod, hand, shadow and body puppets donated by puppeteers and organizations who want to see the art studied and expanded. It also houses the Rufus and Margo Rose Collection, the McPharlin collection, the Chrysler Collection of fully-staged miniature operas, traditional Punch and Judy characters, Neapolitan marionettes, and puppets created by Tony Sarge, Bill Baird and many other world-

YOUR'E NEVER TOO OLD... OR TOO YOUNG DEPARTMENT

The past belongs to the old, and the future to the young, and how hopeful the future looks when you learn about the activities of youngsters whose lives have been affected by Parkinson's disease.

Hot Springs, Ark. I&R coordinator Lydia Stevens, has been receiving checks from Anne and Elizabeth Moses, granddaughters of one of her support group participants. The girls, ages 10 and 12, raised \$250 selling coffee mugs at a recent fund-raiser.

And in Mancos, Colo., 9-year-old Bernadette Bianchi put her feelings in words for her gravely ill grandmother, Margaret, who passed away in March. Mrs. Bianchi, who was 63 when she died, so loved the poem that she asked Bernadette to send it to as many people as she could so they would know more about the terrible disease. Following is Bernadette's poem, "My Grandma:"

*My Grandma used to walk
My Grandma used to talk
Now she lays in bed all day,
Because Parkinson's stole her
voice away.
Now I read her books.
I bring her drinks.
I love my grandma,
But Parkinson's stinks.*

Bernadette is having a garage sale soon as a PD fund-raiser. ■

Mississippi Joins I&R Network Four New Coordinators Named

APDA welcomed Vicksburg, Miss., to the Information & Referral (I&R) network recently with the opening of a Center at the River Region Medical Center under the direction of **Lee Vouters, MD. Brenda Allred, RN**, is the coordinator.

The Center is the first formal resource for movement disorders in the state. Dr. Vouters, a board certified neurologist and the only movement disorder specialist in the state, is a clinical assistant professor of neurology at the University of Mississippi Medical Center, and medical director of River Region's acute rehabilitation unit. Brenda brings more than six years, experience in healthcare management. She is an alumna of Hinds Community College, Raymond, Miss.

Lisa Brovold, senior administrative assistant at Creighton University Medical Center's cancer center, has been appointed coordinator of the Omaha, Neb. I&R Center. Lisa has been affiliated with the university for more than a dozen years in numerous departments including the departments of medicine, surgery, and the cardiac care center. Her range of experience includes management, editorial coordinator, and accreditation compliance. **John Bertoni, MD, PhD**, director of

the medical center's movement disorder clinic, is the I&R Center's director.

Jessica R. Hahn has been named coordinator of the I&R Center at the University of Wisconsin Medical School. Jessica has a bachelor of arts degree from the university and will be applying her organizational and managerial skills to the Center. **Dr. Edwin B. Montgomery, Jr.**, a member of the APDA Scientific Advisory Board and 2004 Roger C. Duvoisin, MD, Fellowship recipient, is the Center's director.

Susan Curry, RN, is replacing **Karen Rodkey, RN**, as coordinator at the Philadelphia (PA) I&R Center at Crozer-Keystone Health System. Karen served in the position for four years. **Dr. Norman Leopold**, director of the hospital's movement disorder program, is the Center's director.

Sylinda Lee is bringing a long list of achievements to the coordinator's position in Salt Lake City. In addition to her bachelor of science degree in community health education from Utah State University, Sylinda has experience as a reporter, was in program development, health education counseling and public speaking. **Dr. John Steffens** directs the Center at the University of Utah Health Science Center. ■

Three Events in One Week Keeps New Jersey Coordinator Busy

New Jersey I&R coordinator Elizabeth Schaaf may have set a record for number of events presented in one week. She began with the 18th Annual People with Parkinson's Disease and Family Conference in Somerset, on April 9, an all-day conference. Three days later, she coordinated a "Meet the Artist Gallery Show," reception and luncheon at the hospital. The afternoon event showcased the artists who contributed to the Center's very successful calendar featuring the multimedia talents of persons with PD.

And to round out the week, Elizabeth and Chapter president Bill Lear organized a bus to transport people from around the area who wished to participate in the April 16th Parkinson's Unity Walk in New York City's Central Park.

Elizabeth is also facilitating a teleconference support group, which the Center is providing with DOROT/Caregivers Connections, a not-for-profit organization offering caregiver support via weekly, one-hour conference telephone calls. ■

Be Aware of Fluid Loss

By Nancy Watts, R.N.

Summer will be here soon. Our bodies adapt to the heat by perspiring, and a two percent total loss of body fluids will result in noticeable symptoms, with the intensity of activity increasing the rate of loss.

During this time, it is common for Parkinsonians to complain of dizziness, lightheadness, and sometimes even fainting when changing body positions.

This is especially true for those who do not drink a significant amount of fluids during hot months. Parkinson's disease can affect the autonomic nervous system, which regulates blood pressure, and this can add to the problem.

This condition, called postural hypotension (drop in blood pressure upon standing), may not be recognized by a routine blood-pressure test in a sitting position.

Many times the condition is exaggerated by anti-Parkinson medication, i.e. Sinemet®, Permax®, Stalevo®, Requip®, Mirapex® and Eldepryl®. Seroquel® and Clozaril®, used to treat hallucinations often caused by dopaminergic medications, can also decrease blood pressure.

The term "dizziness" frequently is used loosely. For example, some Parkinsonians complain of "dizziness" when walking. This may be related to an unstable gait rather than to low blood pressure. Feeling dizzy, light-headed or woozy when getting up or changing positions may help differentiate this symptom.

One of the dangers of experiencing postural hypotension is difficulty in balance with subsequent falling and/or fainting. Precautions, therefore, need to be taken to minimize the effects of hypotension, especially

during hot summer months.

If you are experiencing dizziness or light-headedness when changing positions, inform your physician. The following recommendations may be helpful: Check for postural hypotension by taking your blood pressure in a sitting, and then in a standing position. Add salt to your foods to maintain blood volume. Pickles, pretzels and V8 juice are some items high in sodium. Change positions slowly. Dangle your feet or sit at the edge of your bed for a few minutes prior to rising. Drink plenty of fluids throughout the day, aiming for a pint (16 ounces) per waking hour.

Remember that ice-tea, caffeine, and caffeine sodas serve mainly as a diuretic. Wear elastic support stockings. If the blood pressure drop is severe, you may need thigh-high stockings, which should be put on in the morning. Keep the head of the bed elevated at a 30-degree angle by using extra pillows or adding blocks under the legs of the head of the bed. Sometimes an electric bed may be needed.

Many times patients may need a blood-pressure or fluid-pill adjustment from what they have been on for many years. The physician may also need to add medications to aid in maintaining blood pressure, such as Proamatine® or Florinef®. An adjustment to the anti-Parkinson medications may also be required.

To all of you avid gardeners, golfers, and tennis players, enjoy the summer, but do not stay in the heat too long without plenty of fluids! Be sure to rest often, wear sunscreen, and keep water bottles on hand at all times. ■

Article originally published in the Spring 2004 Issue of Parkinson's & Us, Atlanta, GA.

TREMOR AND PD

continued from page 2

as a speaking engagement. If these are ineffective or produce too many side effects, the doctor may try other drugs. Alcohol also reduces the tremor, and some find a glass of wine before dinner makes eating easier; however, this approach naturally has its limitations.

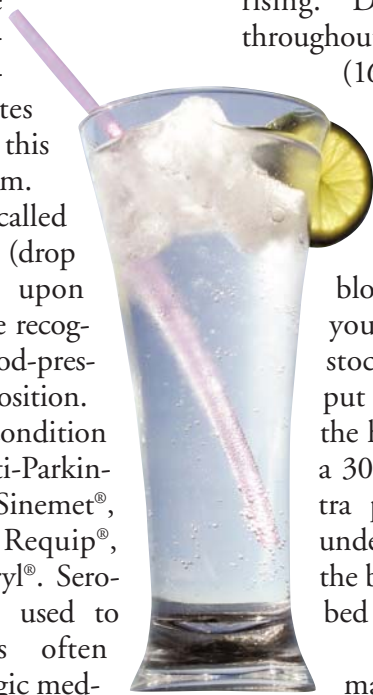
Botulinum toxin (Botox)® injections are sometimes used for head and arm tremors. There is also a surgical procedure called deep brain stimulation that helps in reducing, or even eliminating essential tremor.

Whether you have essential tremor or Parkinson's disease, the future looks hopeful. Research in both areas is promising and effective, and treatment is available for both conditions. ■

NATIONAL INSTITUTE OF HEALTH RESEARCH ON PARKINSON'S DISEASE

Genetic Studies: If you have Parkinson's and know of two or more members of your family with it, National Institutes of Health (NIH) scientists are looking for genes that may lead to Parkinson's disease. If you are interested in participating or have any questions, please call Aileen McInerney-Leo at the toll-free number: 1-888-226-6249, or 301-402-0160

Multicenter Clinical Trial: The National Institute of Neurological Disorders and Stroke (NINDS) offers a section of its Web site devoted to patient recruitment for the Neuroprotection Exploratory Trials in Parkinson's disease (NET-PD) clinical research studies. The NET-PD page will be featured under the Highlights section on the NINDS home page at www.ninds.nih.gov. The direct link is <http://parkinsontrial.org>. ■



ELECTRICAL STIMULATION AVAILABLE FOR SWALLOWING DISORDERS

By Steve Glance, MD, CCC

An estimated 15 million adults in the United States have difficulty swallowing. It is a frequent symptom in Parkinson's disease, stroke, traumatic brain injury, cerebral palsy and other degenerative and muscular conditions.

Severe dysphagia can lead to aspiration pneumonia, dehydration and malnutrition.

Its severity ranges from mild-discomfort swallowing to a complete inability to swallow. The symptoms include:

- Coughing when swallowing or after swallowing
- Choking on food or liquid
- Feeling as if food is getting stuck in the throat
- Pain during swallowing
- Sensation of having a lump in the throat
- Onset of pneumonia of unknown origin.

Until recently, swallowing problems were often managed medically. A new FDA-approved treatment for swallowing disorders uses a small current, passing through external electrodes on the neck. This therapy must be done by a certified medical professional. ■

Adapted from the 2004 Fall Issue "Glory B" APDA I&R Newsletter," Fountain Valley, I&R Center.

MATCHING GIFTS

Many companies and corporations will match your tax-deductible gift and double or triple the amount contributed to continue the APDA mission To Ease the Burden — To Find the Cure. Gifts can be in memory of a loved one or friend or to celebrate a special occasion. A card is sent to the designated person telling him or her of your generosity and thoughtfulness. ■

Scientific Advisory Board Adds Three Members

APDA's Scientific Advisory Board (SAB) added three members at its May annual meeting in New Jersey.

SAB chairman G. Frederick Wooten, MD, professor and chairman of the University of Virginia Health Sciences Center's department of neurology, noted that the board composition is designed to represent expertise in all areas of PD research, providing a knowledgeable panel to evaluate research awards.

"Our new members bring a wealth of academic, clinical and scientific expertise in areas where new research is growing," Dr. Wooten said.

Laura Marsh, MD, is associate professor of neurology at Johns Hop-

kins University School of Medicine, Baltimore, and attending psychiatrist in its geriatric psychiatry program.

Un Jung Kang, MD, is the University of Chicago Medical Center's associate chair of neurology and associate professor in the departments of neurology and neurobiology, pharmacology and physiology.

Evan Yale Snyder, MD, PhD, is the Burnham Institute's stem cell and regeneration program director in La Jolla, Calif.

The SAB reviews Centers for Advanced Research activity annually and evaluates and recommends individual and fellowship awards to the APDA board of directors. This year more than \$2.5 million will be awarded to research. ■



Dr. Kang



Dr. Snyder



Dr. Marsh

NIH Clinical Study

NIH is currently recruiting Parkinson's disease patients who experience abnormal movements caused by Levodopa. The compound, ACP – 103, that is being studied can change the spread of certain brain signals. A total of 46 healthy males and eight subjects with Parkinson's has received the

drug. The study is eight weeks long, one overnight each week. Transportation can be arranged.

For more information contact Caroline Jackins, RNC, phone: (301) 451-2069 or (800) 362-3479 or (301) 496-4604, e-mail: JackinsC@NINDS.NIH.GOV. ■

A Five Year Study of Deep Brain Stimulation

Deep brain stimulation (DBS) is one of the most significant advances in the treatment of Parkinson's disease (PD).

Scientists who pioneered the technique have published findings of a five-year study in the Nov. 13, 2003 issue of the *New England Journal of Medicine*. In the study, Dr. Paul Krack and associates at the University of Grenoble followed 49 patients with a median age of 55 who had bilateral stimulation of the subthalamic nucleus performed between 1993-1997.

The study found that at five years from implantation, tremors had improved by 75 percent, rigidity by 71 percent, and akinesia by 49 percent when patients were in the "off-medication" state, meaning they were not taking levodopa, the standard drug treatment for Parkinson's disease. Postural stability and gait improved, and the percentage of those experiencing painful dystonia while off medication was reduced from 71 percent before surgery to 33 percent at five years after surgery.

When patients were assessed in the "on-medication" state, the duration and severity of dyskinesias decreased at one year after surgery and remained stable at five years.

Because stimulation settings were stable after the first year and throughout the study, these findings indicate that patients do not develop a tolerance to stimulation, and that the positive response can be sustained for five years.

According to Dr. Krack, this means that after five years, the stimulation is still effective and the parameters are stable over time.

Dr. Lang, a professor of neurology at the University of Toronto who wrote an accompanying editorial to

the study, concurs with Dr. Krack that the study shows that DBS results in long-term benefits of greater than five years to all of the features of Parkinson's disease that respond well initially to this therapy. Its major advantage is the pronounced improvement seen in motor complications experienced with long-term levodopa therapy off periods is reduced and levodopa-induced dyskinesias is improved. Tolerance does not occur with deep brain stimulation in that the amount of current required did



not gradually increase over time.

Despite these findings, Parkinson's disease continues to progress in those who have undergone DBS in much the same way as it does in those who have not had the procedure.

Speech improved during the first year and then worsened for those patients in the off-medication state. In the on-medication state, motor function did not improve after stimulation and scores for akinesia, speech, postural stability and freezing of gait worsened between years one and five.

According to the report, "The deterioration when patients were on medication in symptoms including speech, postural stability and freezing of gait, is characteristic of the natural history of PD. The effect of levodopa on akinesia, rigidity and tremor tends to remain stable over time, whereas

gait, postural stability and dysarthria worsen and become less responsive to levodopa.

Five patients experienced cognitive decline, with three patients developing dementia. In the remaining patients the dementia score remained stable. Permanent apathy occurred in five patients after the third postoperative year. One person committed suicide. Researchers speculate that the cases of progressive cognitive deterioration and permanent apathy probably reflect the natural progression of the disease.

The subthalamic nucleus stimulation is not a cure and progression of the disease cannot be stopped, according to Dr. Krack, in patients who do and do not receive DBS alike. New signs can appear, such as speech or gait problems that can be resistant to both medications or stimulation.

The study's authors make the following recommendation for those considering the therapy: "DBS seems most useful for relatively young patients who have motor complications from levodopa and who are independent in activities of daily living in their best on-medication state. Those who already have disabling motor signs that are resistant to levodopa, or who have cognitive deterioration, are not good candidates for DBS."

The treatment also is recommended for older patients who are in good health and whose Parkinson's symptoms respond to levodopa.

Those considering surgery need to have realistic expectations of the outcome, and even after brain surgery they will have to live with a chronic neurodegenerative disease with levodopa therapy as a crucial component of treatment.

For more information please call 1-800-328-0810 (Medtronic). ■

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 Fax 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 in Parkinson's Disease**
26-page booklet (English, Italian, Swedish)
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. **My Mommy Has PD... But It's Okay!**
20-page booklet for young children.

EDUCATIONAL SUPPLEMENTS

Hospitalization; 34 Helpful Hints; Living Will; Helping Your Partner; Adapting to a Nursing Home; Comtan (Entacapone) The Treatment of Parkinson's Disease: Question and Answers; Comtan: Extending the Benefits of Levodopa; Comtan (Entacapone) Tablets and the Quality of Life in Patients with Parkinson's Disease; 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.

CARELINK (A cooperative APDA-GSK project)

You can now contact the APDA Information and Referral Center closest to you by dialing the toll-free number 1-888-400-APDA (2732)

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

PATIENTS PREFER AN ORALLY DISSOLVING CARBIDOPA- LEVODOPA FORMULATION

According to a clinical study published in the January 2005 issue of Clinical Therapeutics, more than twice as many Parkinson's disease patients prefer Parcopa™ (carbidopa-levodopa orally disintegrating tablets) to conventional carbidopa-levodopa tablets. The reason primarily influencing their preference was more rapid access to medication to treat "off" times, less interference with daily activities, convenience for nighttime dosing and the feeling of being less conspicuous about using of medication. Parcopa is a Schwarz Pharma, Inc. formulation of carbidopa-levodopa that dissolves on the tongue without the need for water. (See the Winter 2005 APDA Newsletter Issue.)

A \$20 coupon is available for Parcopa at www.parcopa.com or by calling 1-877-727-2672. ■

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 physician.