

Botulinum Toxin In Parkinsonism

By Alan Freeman, MD

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Botulinum toxin (BTX) has been successfully used for hyperkinetic movement disorders for more than 20 years. Botulinum neurotoxin is produced by the anaerobic bacillus Clostridium botulinum. There are seven botulinum stereotypes labeled A-G. Two forms of BTX A and B have been approved for clinical use. BTX A is available worldwide as Botox® (Allergan), in Germany as Xeomin® (Merz pharma) and elsewhere as Dysport® (Ipsen). Botox is the only form of BTX-A currently available in the USA, although other forms may be available for therapeutic use next year. A formulation of BTX B is also available in the USA as Myobloc® and in Europe as NeuroBloc® (Solstice). BTX Types C and F have also been used in humans, but only on an experimental basis. The US Food and Drug Administration (FDA) has approved Botox for the treatment of blepharospasm (forced eyelid contractions), cranial nerve seven disorders (hemifacial spasm), cervical dystonia (involuntary neck spasm), and hyperhidrosis (sweating) and Myobloc for the treatment of cervical dystonia.

Other uses of BTX are being investigated, but none has been approved by the FDA. Some of these include spasticity, headache, sialorrhea (drooling), tremor, overactive bladder, limb dystonia, and tics.

BTX works by inhibiting acetylcholine release at the neuromuscular junction and salivary/sweat glands. This causes temporary paralysis of the muscles and a decrease in secretion of the glands. The duration of effect varies but is usually 10-20 weeks (for involuntary movements and excess salivation).

Doses of BTX are dispensed in units. The units of each form of BTX are not clinically equivalent; therefore, the different formulations are not interchangeable. In addition, each formulation has different diffusion and side effect profiles.

Botulinum toxins may be used in idiopathic Parkinson's disease (PD) as well as atypical parkinsonian syndromes, as progressive supranuclear palsy. Patients who develop blepharospasm, from either the primary illness or medications, can be successfully treated with BTX and are typically injected with small doses of toxin approximately every three months.

(Continued on page 2)

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Botulinum Toxin in Parkinsonism *(Continued from pg. 1)*

Drooling can be a major problem with advanced PD. Both Botox and Myobloc have been successfully used in this condition. Myobloc may have an advantage, with its side effect of dry mouth, seen when used to treat cervical dystonia. We were recently involved in a Myobloc sialorrhea study for PD, and preliminary results look very promising.

Botulinum toxin can also be used in cervical dystonia in patients with progressive supranuclear palsy, and in limb dystonia with PD and parkinsonian syndromes.

This includes the “dystonic clenched fist” in the upper extremity and foot inversion or toe flexion/extension in the lower extremities.

Once the FDA approves new uses for BTX, it will be much easier to get reimbursement from Medicare and insurance companies. Hopefully it will be in the near future.

Note: This article was adapted from one published in the APDA Atlanta, Ga I&R Center newsletter, Winter/Spring 2009. ■

Health Literacy in the Elderly

According to the US Department of Health, the elderly are less likely than younger populations to have a proficient level of health literacy. The 2003 Health Literacy Component of the National Assessment of Adult Literacy (NAAL) showed that over one-quarter of adults age 65 and over had “below basic” health literacy. There is evidence that inadequate health literacy is linked to all-cause mortality among the elderly.

NAAL groups adults into four performance levels:

- Below basic – A person can understand no more than the most simple and concrete skills. Thirty million adults were found to have below basic health literacy; 7 million of these were unable to answer the simplest of questions and were non-literate in English.

- Basic – A person can perform the skills necessary for simple and everyday activities. Forty-seven million adults were found to have basic health literacy.

- Intermediate – A person can perform the skills necessary for moderately challenging activities. One hundred and fourteen million adults were found to have intermediate health literacy.

- Proficient – A person can perform the skills necessary for more complex and challenging activities needed to manage health and prevent disease. Twenty-six million adults were found to have proficient health literacy.

- Only 12% of adults had proficient health literacy, in other words nearly 9 out of 10 adults may lack the skills needed to manage their health and prevent disease.

Abstracted from the 2007 National Healthcare Disparities Report Agency for Healthcare Research and Quality, Department of Health and Human Services USA ■

Mediterranean Diet and Parkinson’s Disease

The review of 12 studies evaluating overall mortality in relation to adherence to a Mediterranean diet showed beneficial role of this diet on cardiovascular mortality and the incidence of cancer, of Alzheimer’s disease and of Parkinson’s disease, a 13% decrease for this disease.

These results seem to be relevant for prevention of major chronic diseases. ■

Nicotine and Parkinson’s Disease



According to recent studies, published by the Parkinson’s Institute, nicotine may be of therapeutic value in Parkinson’s disease. Epidemiological studies show an inverse correlation between the use of tobacco and Parkinson’s disease. Several studies also suggest a symptomatic effect of nicotine in Parkinson’s disease, although such effect is small and somewhat variable.

Data in nonhuman primates show that nicotine decreases levodopa-induced dyskinesias, a debilitating side effect that develops in the majority of patients on levodopa therapy. ■



Dear Reader:

Psychologists tell us that there is a common recurring dream some people experience. They are being chased by a threatening force and

whenever they think they have outrun or outsmarted that threat, they turn around and it is behind them and the flight begins all over again.

I think many of us feel just that way right now.

For eight years research that might benefit Parkinson's and other diseases and conditions was limited on ideological grounds by government ruling. Now that the federal government has lifted that ban, financial reasons are impeding the flow of corporate and private dollars.

People cannot contribute to a cause unless they have something to contribute, and no one expects a contribution in lieu of someone eating or paying the rent. In times such as these, however, giving is often curtailed not because of need, but because of fear of the future.

For people with PD and other diseases, however, research for a cure is the only hope.

We are grateful that our supporters are making it possible for our continued funding of nine centers for advanced research, medical student summer fellowships, Cotzias fellowships and Divoisin grants during these difficult financial times. We will be funding \$1.5 million in research next year while other organizations and indeed, prestigious foundations and corporations have been forced to eliminate and even repeal some awards.

APDA is determined also to meet its mission of patient support. We may be forced to tighten in some areas – we hope temporarily – but we will continue to provide Information & Referral Centers and support groups, free educational materials, programs and patient/caregiver support.

And with a little help from our friends and supporters, we will outrun and outsmart this threatening force called Parkinson's disease once and for all.

Sincerely,

A handwritten signature in black ink, appearing to read "Joel A. Miele Sr.", written over a light-colored background.

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

MEDICATION PATCHES AND MRI BY: LAURAN NEERGAARD – ASSOCIATED PRESS

Need an MRI scan? Tell the doctor if you use a nicotine patch or any other medication patch, or you'll risk a burn during the MRI.

Patches that deliver medications slowly through the skin are becoming more popular, from over-the-counter nicotine patches to prescription patches that deliver estrogen, pain medication, Alzheimer's or Parkinson's drugs, even an anti-nausea drug for chemotherapy patients.

The Food and Drug Administration just discovered that some of these patches are missing a safety warning about MRI compatibility.

More than a quarter of the 60 different drug patches sold contain traces of aluminum or other metals in their backing, the part that makes them stick to

the skin, estimated Dr. Sandra Kweder, the FDA's deputy drug director.

The affected patches contain just enough metal to conduct electricity, meaning a patch worn during an MRI scan can overheat and cause a skin burn similar to a bad sunburn.

The FDA issued a public warning on notifying the healthgiver about any medication patches, so he/she can decide which should be removed before an MRI, how long before the scan, and when it can be reapplied.

"If there is any uncertainty, just don't wear it in the machine," Dr. Kweder said. "It's just the smart thing to do." ■





BY ENRICO FAZZINI, DO, PhD
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Q. My wife who was recently diagnosed with Parkinson's, also has diabetes. She takes Sinemet 25/100 for her Parkinson's and it seems to us that medication has increased her blood sugar. Her GP just increased her Lantus Solostar from 30 to 35 units daily in trying to decrease her sugar readings. The change has been minimally effective and it seems her sugar readings are still high and undulating. We recently had to reduce her Sinemet from 1 tab 3 times per day to ½ tab 3 times per day because she tended to sleep all day at the higher level. Her hand tremors have returned at an acceptable level at the lower dosage, but she is still too sleepy during the day after sleeping well all night. Is there any information available regarding the combination of Parkinson's and diabetes which might help both her neurologist and her general practitioner?

A. There is no effect of Sinemet on raising or lowering blood glucose levels. There is no association of diabetes and Parkinson's disease. Having said that, I have seen patients with diabetes and PD develop "off" periods in which blood levels of L-Dopa and glucose fall, I always tell patients with diabetes and PD to assume that they are hypoglycemic during such an attack so as not to confuse hypoglycemia with the "off" period from having too little Sinemet. Insulin does increase the penetration of dopamine into the neurons and that is why patients with PD find that they get an additional boost from their PD meds after eating sweets. In terms of the sedation – you do have a problem if such a tiny dose of Sinemet (1/2 of a 25/100 tablet) produces excessive sedation; you can try Sinemet CR 25/100 as this would have a smoother onset, or you can give the Sinemet closer to bedtime as long as it does not make her dream. The sedation may be due to diabetes with

fluctuating blood glucose levels and low blood pressure.

Q. I am particularly interested in the possibility of me getting Parkinson's. My mother and my uncle (my mother's brother) both suffered from Parkinson's. I have been told that it is not hereditary but there is a propensity to get the disease.

A. Young onset (under 40 years old) patients with Parkinson's disease have the greatest inheritance factor with up to 50 percent of those patients carrying the defective genes for the regulation of transportation of dopamine in the neuron (parkin). However, up to 20 percent of older onset patients may have another gene defect that affects how the mitochondria respond to stress (LRRK2). In general, if you have a parent and a sibling with Parkinson's disease, your risk is almost 25 percent for developing PD.

Q. What exercises, diet or other methods can I do to help me from getting Parkinson's disease? Now my hands tremble a great deal. This was how my mother started.

A. There is no proven way to prevent the onset or slow the progression of Parkinson's disease, but I would take antioxidants including Selegiline or Rasagiline, Coenzyme Q-10, anti-inflammatory agents like Ibuprofen, and continue to eat a healthy well-balanced diet, exercise and try to reduce stress as much as possible. Your tremor may not be a resting tremor; most likely it is an action tremor not associated with any other neurological problems (essential tremor). Your mother may have had a similar tremor for many years before developing a resting component of that tremor and bradykinesia, ie. Parkinson's disease. ■

Meet Jacob I. Sage, MD APDA Scientific Advisory Board Member

It is not common for a medical researcher to spend an entire career at one institution, but Jacob I. Sage, MD is not a common scientist and physician.

Neurology professor and director of the UMDNJ-Robert Wood Johnson (RWJ) Medical School, Dr. Sage was born, raised and attended high school in the Garden State, leaving only to earn his bachelor's degree at the University of Chicago and medical degree from the University of Pittsburgh. Additional postgraduate training took him to Yale-New Haven Hospital in Connecticut, Temple University Hospital in Philadelphia and Cornell Medical College in New York City, but then he returned home where he has worked for more than 29 years.

It was not just homesickness that kept him at RWJ; it was there that he met and began to work with Dr. Roger Duvoisin, who pioneered the association of genetics with Parkinson's disease and was one of the team at RWJ that discovered the presence of Alpha-synuclein in the disease.

"These were truly revolutionary breakthroughs," Dr. Sage says.

He is the vice chairman of APDA's Scientific Advisory Board, director of its Center for Advanced Research at RWJ, and serves as the Information & Referral Center's medical director. He has been recognized for his service to APDA and honored by the Dystonia Medical Research Foundation, the American Academy of Family Physicians

and twice received the Neurology Resident Teaching Excellence Award.

While focusing on his research, which has brought \$4.5 million to the school in research grants, education is also a major part of his personal mission. Under his sponsorship, six RWJ Medical School graduates completed postdoctoral fellowships, among them Dr. Rocco DiPaola, who is in private practice as a movement disorder specialist in southeastern N.J. and Dr. Machteld Hillen, an associate professor on the UMDNJ-New Jersey Medical School faculty in Newark.

But the doctor's research isn't limited to levodopa and dystonia. He has a green thumb that he puts to work in his one-acre vegetable garden, and he and a neighbor will be experimenting with 40 different varieties of heirloom tomato seeds this summer. (Ed. note: It won't receive grant funding, but we hope to give a report on their success in our Fall Newsletter.)

Dr. Sage and his wife, Cynthia, have three daughters, Naomi and Rebecca, who have completed their studies and Abigail, who is following in dad's footsteps as a pre-med student at Rutgers University. ■



Dr. Sage

Awareness in April

Last month was Parkinson's Awareness Month, and APDA's Chapters and Centers rose to the task arranging for legislative proclamations, sponsoring educational programs and accomplishing media placements across the country. As of mid-April 14 state and 25 city and local proclamations were issued.



Connie Srote and Nita Heap listen as Mayor R. Bruce Boyer, left reads his proclamation for Parkinson's awareness in Brunsfel, Texas



Dallas Mayor Tom Leppert, left, poses with members of the Dallas Chapter and I&R Center at Baylor Hospital following his proclamation. With him, from the left, are Dr. Madhavi Thomas, I&R Center medical director, chapter president David Blaylock, coordinator Keesha Paul, and national board first vice president Fred Greene.

IN THE WEST

April is especially important for people with, and people associated with Parkinson's disease, but their needs and support are year-round. Jo Bidwell's 15 years of service in western Texas and eastern New Mexico were recently acknowledged with a \$2,000 contribution in her honor by the Amarillo Support Group. "We have reaped great rewards from her efforts," noted its letter. In addition to her work as the Lubbock, **Texas** Information & Referral Center coordinator, Jo has been a member of South Plains College's science faculty for more than 20 years and is the busy mother of a daughter Lara, a high school junior, and son, Josh, a University of Texas junior.

IN THE SOUTHWEST

Nevada I&R Center coordinator Jeri Giallanza convened three experts from different fields for a comprehensive workshop addressing "Aging, Dementia and Law." Neurologist Charles Bernick, MD, certified elder law attorney Kim Boyer, and geriatric care manager Mary Shapiro spoke last month in Las Vegas. "Living with a chronic illness can make an individual and his/her family feel helpless," said Ms. Shapiro, "but knowledge is power, and the more you learn to listen, face your fears and ask tough questions, the stronger you are."

The **Arizona** chapter's spring conference, "Power Over Parkinson's", attracted more than 300 people, and no wonder, with its array of experts. Journalist and producer of PBS's "My Father, My Brother and Me," David Iverson, was the keynote speaker, and the program included a potpourri of topics including research updates, politics and medicine, tips for living with PD, and yoga laughter. Last month the Green Valley/Sahuarita support group sponsored a research fundraiser, give "Parkinson's the **SAC**" – mentally Stimulated, physically Active, and Socially Connected.

IN THE NORTHEAST

The Central Susquehanna Valley **Pennsylvania** Support Group started the year with a successful deep brain stimulation lecture by Kelly Conderfer, MD, at the Geisinger HealthSouth Rehabilitation Hospital in Danville. The only admission the group sought was in



Dr. David Rintell, right, a clinical psychologist at Brigham and Women's Hospital in Boston, answers a participant's question after his address "Resilience and Parkinson's" at last month's New Jersey's "Living Well With Parkinson's" spring conference.

collecting recipes for a cookbook fundraiser.

Maine's annual Parkinson's Awareness Conference continues to grow in its seventh year. The full-day event in South Portland had a varied program including speakers addressing deep brain stimulation, research and surgical updates, non-motor issues, and workshops on finding community resources and PD and the workplace. Author Janet Edmunson was the keynote speaker.

Maureen Chamberlain, the **New Hampshire** Chapter president led a candlelight vigil at the State House in Concord, following Gov. John Lynch's proclamation.

IN THE NORTH

I&R Coordinator Paulette Olsen reports a busy April schedule throughout the state of **Minnesota** that included a visit to the Capitol, free screenings, a conference in Duluth and public forum in Northfield, and she is now gearing up for the spring conference June 6. "Parkinson's: Early and Late, Anticipating an Unknown Journey" will take place at the Radisson Hotel in Roseville. Paulette can provide details at paulette.olsen@allina.com.

IN THE SOUTH

Scarlet O'Hara may have been clever turning draperies into a gown during the Civil War, but the innovative APDA Gulfport **Mississippi** Support Group has done her one better in an economic downturn. Janice Barnett offered the "Stamp Out PD" car magnets she received as awareness giveaways at the Mississippi

(Continued on page 8)

Choosing Your Estate Executor

JOHN Z. MARANGOS, ESQ.
APDA THIRD VICE PRESIDENT

It is widespread knowledge that everyone, regardless of how small an estate he/she will leave, should have a will. Equally important, however, is who should be the executor of your will.

Your executor is designated to marshal your estate's assets after paying any debts, taxes and other financial obligations, distribute those assets, and file an accounting with the court; in other words, someone you trust to carry out your wishes on your behalf.

Being designated an executor is both an honor and a responsibility. Depending on the complexity of the estate, it can involve a lot of time and expertise, especially if it involves a business and/or investments.

The executor is a fiduciary role and is accountable to the beneficiaries so that the estate is disposed of in their best interests.

For example in today's financial environment, an executor would not be accountable for a sharp decrease in a stock portfolio, but if he/she took the assets to Atlantic City, gambled to increase them and lost, the executor would be liable.

While an executor's compensation can range from 2 to 5 percent depending on the net assets, a very large or complex estate can demand considerable time and work.

This compensation is subject to income tax. Where the executor is also a beneficiary, he/she often waives compensation allowing for a larger distribution that is not taxable.

Most people choose to have a spouse or adult child as an executor, there should always be at least one alternate named. If there is uneasiness in choosing among children, people may ask their attorney or accountant

to assume the role.

Should you want to include a not-for-profit organization, it is recommended that you verify the legal identity of that entity. A large national organization may have offices, branches or chapters in different states. Also, if you wish a specific program to receive your gift, such as for research, education, or patient support, be certain that you restrict your gift accordingly. The executor may know what you wanted, but unless it is stated in your will, the gift will be given to the organization for its general operations.

When deciding upon an executor, it is important to ask two questions: does this person know my wishes; and, is he/she willing to undertake the responsibility of carrying them out?

Once that decision is made, you should review your will whenever there is a life change such as a marriage or divorce, birth, death or retirement, and, in general, every 10 years to be certain that your wishes haven't changed and your executor is still able and willing to serve as such. ■

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.

We have chosen the breathtaking red tulips with a small white edge, the traditional symbol of hope for Parkinson's disease. These mid-spring bloomers produce egg-shaped flowers on 20-to-24-inch stems and are appropriate for planting in containers for balconies and patios as well. Packages contain 25 top-size bulbs, and make wonderful gifts.

The best part is that APDA will receive 40 percent of the price (excluding shipping cost) of every package of tulips purchased. So, when planting your beautiful tulip bulbs, you are also planting hope for the cure.

Share this offer with friends and family and help Parkinson's research even more. The package (bulb \$29.95, includes all shipping and handling charges. Orders must be received by September 15, 2009.

Two ways to order:

1. Order online at www.tulipworld.com/APDA
2. Call toll free 1-866-688-9547.

Tulip **APDA**

Disability NOT Diagnosis

By JULIE SACKS
DIRECTOR, APDA
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People often have the misconception that disability entitlement is based on a diagnosis. This is not the case. While the Social Security Administration (“Administration”) requires that an individual have a severe medically determinable impairment, what is most important is the limitation that the impairment imposes.

The Administration recognizes that Parkinsonian Syndrome is degenerative and progressive in nature. It, however, also recognizes that many people who have Parkinsonian Syndrome do work and can maintain a work schedule for many years following a diagnosis. The Administration must determine at what point a person becomes vocationally disabled. Essentially, the Administration will grant benefits when an individual is unable to complete a normal workweek because of his/her symptoms.

The Administration uses many tools to make such a determination.

First, it will examine a claimant’s medical records for clinical and laboratory evidence indicating disability. The Administration will see if the records indicate rigidity or tremors, which interfere with fine and gross manipulation or gait and station. It may also look to see if there is any cognitive impairment evidenced in the medical documentation.

Second, the Administration may request an opinion from a treating physician as to an individual’s limitations and capabilities.

Third, the Administration, at its own initiative and cost, may send an individual to a consultative examination with a doctor for an evaluation of limitations.

Finally, the Administration may solicit the help of a vocational expert to determine whether an individual can maintain employment in spite of his/her limitations. This is just some of the analysis that goes into determining whether an individual is capable of working. It is, however, illustrative of the Administration’s reliance on limitations, opposed to a diagnosis, in determining disability. While the diagnosis is important, a diagnosis alone will not entitle a person to disability benefits. ■

Around The Country *(Continued from page 6)*

statewide support group meeting in Hattiesburg to friends for a \$5 Chapter donation. Ed Ouimette from the Gulf Coast group had a similar thought but didn’t specify a donation amount and received checks in the \$20 range. In all, the chapter realized almost \$200 – pure profit from giveaways! The chapter is sponsoring a regional conference June 20 in Greenwood, Miss. with Ronald Pfeiffer, MD, John Norton, MD, and the Rev. Susannah Grubbs Carr. Patsy Cline imitator Naomi Barnette will provide the entertainment. And, if that isn’t varied enough, there is an optional cooking class June 19. ■

APDA and NPF Collaborate to Offer First Joint Young Onset Conference

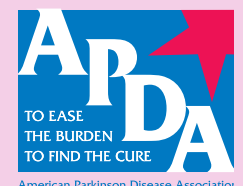
APDA, which sponsors the only national young onset center addressing the needs of young people with PD and their families, and the National Parkinson Foundation (NPF), which has sponsored national young onset conferences for six years, have joined forces. This first-ever cosponsored young onset series will be in Dallas Oct. 23 and 24, 2009, with three more programs in other parts of the country to be scheduled during 2010.

Joel Gerstel, APDA executive director, and Joyce Oberdorf, NPF president and CEO, announced the series in March.

The Dallas conference, “Choices and Connections,” will include a live Webcast to extend its audience reach to as many patients as possible.

Each program in the series will combine the latest information about the science of the disease and medical updates, with panel discussion about work/disability issues, managing stress and relationships, and how to deal with the strain of being a caregiver.

The \$30 registration fee will include all conference materials, a welcoming reception, continental breakfast and lunch. More information is available on APDA’s Young Onset Center’s Web site, www.youngparkinsons.org. ■



Questions for the Neurologist

BY LAWRENCE GOLBE, M.D.
PROFESSOR OF NEUROLOGY, UMDNJ-
ROBERT WOOD JOHNSON MEDICAL SCHOOL
NEW BRUNSWICK, N.J.



If you have recently received a new diagnosis of Parkinson's disease (PD), you have a lot of homework to do. Although the emotional side of you will want to ignore or minimize the illness, the intellectual side of you should tackle it head-on. In fact, taking control of your PD can help you deal with the emotional stress.

PD is a complicated illness. It eventually may affect many parts of the brain. Even at the point that the classic clinical symptoms such as slowness, stiffness and tremor first appear, there is evidence that the disease has already affected many lower parts of the brain that control such functions as mood, smell ability, blood pressure, bowel function, bladder function, erectile function and sleep.

So here are a few questions to ask your neurologist over the course of the first two or three visits. At this stage of PD, visits should occur no less frequently than every two or three months in order to allow you to ask questions of the doctor even if no medication is required.

Could this be a different Parkinsonian condition that is treated differently than PD or may even be curable?

Treatable conditions that can mimic PD include multiple, tiny strokes, the effects of drugs such as certain anti-nausea agents or tranquilizers, normal-pressure hydrocephalus, masses such as tumors or blood clots, and a rare hereditary condition called Wilson's disease.

What is causing the symptoms?

Your neurologist should explain our current knowledge of what is making brain cells malfunction or die off in PD and where.

Are there any dietary recommendations?

Dietary manipulations can help avoid the constipation that can result both from PD and from some of its medications.

How long before I experience some disability?

This will be a gradual process that will depend not only on your response to medication, but also on what new medications will become available over the next few years. However, your neurologist can provide statistics based on past experience in large numbers of patients.

How do I know when it's time to start taking medication?

Neurologists differ on this issue. Some feel that med-

ication should start at the time of diagnosis, and others wait for important interference in one's daily activities. There are pros and cons for both views.

Is PD hereditary?

The answer is, "a little." Your neurologist should take a detailed family history. If you have any relatives with PD, the risk to your healthy siblings and children is greater than if you are the only one in your family with PD to date.

Should I get a genetic test?

There are commercially available tests for only two of the several known genes that can cause PD. These account for only a tiny fraction of all PD. You should discuss with your neurologist what you and your family would do with the knowledge that you carry one of these genetic defects, should the test be positive.

What should I read to learn more about PD?

There are several excellent books on PD for patients and their families. Your doctor may know one or two to recommend or may refer you to one or more of the national PD organizations, such as APDA, which have educational printed material that you can download or have mailed to you.

This article was adapted from the APDA New Brunswick, N.J. APDA I&R Center Summer newsletter. ■

DEEP BRAIN STIMULATION

Potential Problems

Michael Frank, Ph.D., an assistant professor of psychology and director of the Laboratory for Neural Computation and Cognition at the University of Arizona, led a research team that has shed light on how deep brain stimulation (DBS) interferes with the brain's innate ability to deliberate complicated decisions. His collaborators included Scott Sherman, MD, Ph.D., and Johan Samanta, MD, faculty members in the department of neurology and directors of the APDA I&R Centers in Tucson and Phoenix, AZ.

When medicine fails Parkinson's patients, DBS often is the only step left for relief from symptoms. However, a troublesome downside is that DBS patients often exhibit compulsive behaviors that healthy people and those taking medication for Parkinson's can easily manage.

DBS implants affect the region of the brain called the subthalamic nucleus (STN), which also modulates decision making. "This part of the brain regulates the 'hold-your-horses' signal," Dr. Frank said. "When you're making a choice between two or more conflicting options, normally your system says, 'Hold on for a second. I need a little more time to sort this out.'"

The STN detects conflict between two or more choices and reacts by sending a neural signal to temporarily prevent the selection of any response. It's this response that DBS seems to interrupt. DBS acts much like a lesion on the subthalamic nucleus. Frank's hypothesis is that DBS would negate the "hold-your-horses" response to high-conflict choices, and speed up the decision-making process, leading to impulsiveness.

The tendency toward impulsive behavior in Parkin-

son's patients is well documented but only dimly understood. How is the STN involved in decision making and why should things go awry when you stimulate it?

Dr. Frank noticed that patients taking medications did not learn from negative outcomes of their choices, which could be one explanation for why some patients develop gambling habits. If you learn only from positive outcomes but not from the negative, it could cause you to become a gambler.



"Whereas the DBS has no effect on positive versus negative learning, it had an effect on your ability to 'hold your horses,' so it was a disassociation between the two treatments which we think reveals different mechanisms of the circuit of the brain that we're interested in," Frank said.

These findings were published on a recent issue of Science (vol. 318) and this article was adapted by APDA Coordinator Cynthia Holmes, Ph.D., from a news item which appeared in the Summer 2008 Issue of Parkinson: Participating in Progress, a Newsletter of the University of Arizona School of Medicine. ■

BLACK TEA AND PARKINSON'S DISEASE

A large study in Singapore showed that the use of black tea may decrease Parkinson's disease risk by almost a third.

In the study, people who drank the most black tea were 29% less likely to develop Parkinson's disease (PD), compared to the least enthusiastic black-tea drinkers. Al-



though the researchers were poised to credit the caffeine in black tea for the benefit, it turned out not to be so. Instead, it may be that black tea somehow affects estrogen levels in a favorable anti-Parkinson's way. Interestingly, green tea showed no protective effects against PD.

PARTICIPATING IN A CLINICAL RESEARCH TRIAL

By Kristine Twomey RN, ANP-BC

Coordinator APDA I & R Center in Neenah, Wis.

People with Parkinson's disease (PD) and their caregivers often ask about clinical research studies that are being conducted in the area and how or if they may participate.

Deciding to become a participant in a clinical trial requires very careful consideration and through evaluation of the risks and benefits associated with a given protocol. Some of the questions that you should consider are here reviewed.

The first question to ask will be what are the benefits and more importantly, what are the risks involved with participating in the study. There is no study involving medications or surgery that is without risk and you need to decide what level of risk is acceptable.

Other questions to consider include:

1. What is the commitment and travel required to participate in the study?
2. What are the inclusion and exclusion criteria for participation?
3. Is there any compensation for time and/or travel expenses?
4. Will I be receiving treatment or is there a placebo also?
5. Who will be in charge of my care during this study?
6. How is safety protected during the study?

For more information about being a clinical trial participant visit www.pdtrials.org or www.clinicaltrials.gov and remember to speak with your healthcare provider. ■

PFIZER'S PATIENTS SUPPORT

The number of Americans who are uninsured or underinsured continues to grow. In the months ahead, even more Americans may join this group as some lose their jobs and others see their benefits run out.

Through **Pfizer Helpful Answers®**, Pfizer provides medicines for free or at savings to uninsured people who qualify. Last year Pfizer provided nearly 1 million uninsured individuals with Pfizer medicines worth more than \$891 million.

Connection to Care®, which provides Pfizer

medicines for free to nearly 500,000 people each year now offer Hardship Exceptions for people with limited income who have prescription coverage, but who are facing significant financial or medical hardship so they may qualify to get their Pfizer medicines for free.

It has updated the **Connection to Care®** application, so that now is just one page. Patient proof-of-income requirements have also been simplified.

Pfizer has updated its website www.pfizerhelpfulanswers.com, and now offer a section dedicated to the needs of community groups. ■

VIETNAM VETERANS AND PARKINSON'S DISEASE

Chairman of the House Committee on Veterans Affairs Bob Filner reintroduced a bill that would grant service connection for Parkinson's disease for Vietnam veterans. H.R. 1428 would establish a presumption of service-connection for Parkinson's disease due to exposure to Agent Orange for Vietnam veterans afflicted with this condition.

Approximately 20 million gallons of herbicides were used in Vietnam between 1962 and 1971 to remove leaves and other vegetation that provided cover for enemy forces. Shortly following their military service in Vietnam, some veterans reported a variety of health problems and concerns due to exposure to Agent Orange or other herbicides and pesticides.

"Strong evidence has existed for decades to make the association link between exposure to Agent Orange and other herbicides and Parkinson's disease" stated Chairman Filner. "I believe we need to examine the disconnect between modern medicine and the current provisions which only allow service-connection for chronic conditions that manifest within one-year of service become evident. Modern science clearly establishes that the symptoms of these many degenerative diseases can take decades. Time is running out for many of our Vietnam veterans suffering from fighting for their lives everyday, uncompensated for their sacrifice."

The bill has been referred to the House Committee on Veterans Affairs. ■

Educational Material

Most APDA publications can be downloaded free from our Web site, www.apdaparkinson.org, publications page.

The new APDA's e-newsletter provides timely news about all aspects of PD and a helpful "Tip of the Month." The newsletter is free, and you can unsubscribe any time. Sign up on APDA Web site's home page.

Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling 1-800-223-2732, faxing to 1-718-981-4399, or contacting any of the APDA Information and Referral Centers throughout the United States.



BOOKLETS

1. Parkinson's Disease Handbook (English, German, Italian, Spanish)
2. Young Parkinson's Handbook (English).
3. Be Active (English)
4. Be Independent (English)
5. Speaking Effectively (English)
6. Good Nutrition (English)
7. Aquatic Exercise for Parkinson's Disease (English)
8. My Mommy Has PD... But It's Okay! (English)

SUPPLEMENTS

- The Family Unit
- Hospitalization of a Parkinson Patient
- Fatigue in PD
- Healthy Aging
- Keys for Caregiving
- Neuro-ophthalmology and PD
- Medical Management of PD and Medications Approved for Use in the USA
- Depression and PD

WEB SITES

- www.apdaparkinson.org
- www.youngparkinsons.org
- www.apdawest.org
- www.wpda.org

BROCHURES

- A. Basic Information (English, Spanish, Chinese)
- B. Medications to Be Avoided or Used with Caution in PD
- C. How To Start a Support Group (English)
- D. National Young Onset Parkinson Disease (English)

DVDS

- Managing Parkinson's - Straight Talk and Honest Hope, 2nd Edition

Materials concerning 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.