

PARKINSON

OFFICIAL JOURNAL OF THE NATIONAL PARKINSON FOUNDATION **Report**

Frequently Asked Questions
ABOUT HOSPITALIZATION

More Current Topics
ADDRESSED BY 21 EXPERTS



Vol. XVIII, Issue 3, **Summer 2007**

MARTY ARDMAN

When I learned that my father had Parkinson disease I felt a range of emotions. It was as though I was helpless, powerless to stop the disease that was affecting someone so close to me. At that point I made a decision to take a stand against the disease and to help fight for the cure. My father, Marty Ardman, has been doing that for years by helping to raise thousands of dollars for the National Parkinson Foundation. He volunteers at the Foundation on a weekly basis working closely with NPF Chairman Emeritus, Nathan Slewett. My father has shown me all the amazing work NPF does to help people with Parkinson disease and to help find a cure. I decided I would do the same and raise money for NPF by running in the Nashville half marathon. I was no longer helpless, no longer powerless.

I decided to ask my brother-in-law, Jack Lapidus, and my close friends in Nashville, Jessica Averbuch, Alizah Greenberg, Jessie Rosenblum, and Patti Straus, to join me. After contacting the National Parkinson Foundation, I learned of a wonderful online fundraising tool on the NPF website called "Community Fundraising." I was able to create my own custom web page which allowed me to post pictures, tell my story, and track the donations. Initially, I decided to start small and set my goal for \$1,000; however, my Nashville girlfriends told me that if you dream big anything is possible. We decided on a team name,



"Running Wild," and a new goal of raising \$10,000. We all set off to work, writing a solicitation letter and getting a friend to create a "Running Wild" logo. We then gathered the names and addresses of anyone the six of us had ever known, spoken to, or had even the most remote connection to. Over 1,000 letters went out asking donors to contribute online by visiting our web page or by sending a check. We were shocked by the generosity of the response from people all over the country, many of whom we hardly knew. Every day my teammates and I anxiously waited for the mail and checked the web page for donations. We were amazed to find out how many people, including friends and relatives, have been touched in some way by Parkinson disease.

I am proud to say that team "Running Wild," inspired by my amazing dad, Marty Ardman, raised almost \$13,000 for the National Parkinson Foundation. He is someone who, no matter what the circumstance, always looks on the bright side and sees the glass as half full. He is optimistic in every situation and always lives life to the fullest. My dad is a motivated, determined, hard-working individual who tackles any problem that comes his way. He is, and always has been, a family man who puts his family first. He is loved and respected so much by his family, friends, and anyone who ever meets him. ■

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OFFICIAL JOURNAL OF THE NATIONAL PARKINSON FOUNDATION

Report

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In U.S., Canada and the Caribbean
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Dedicated to Research and Real People

Since its creation half a century ago, the National Parkinson Foundation (NPF) has had the dual mission of finding the cause and cure for Parkinson disease and of helping those who must deal with that disease every day of their lives. For the last few years our general policy in that respect has been to devote one-half of our mission-related expenditures on research and one-half on patient services.

We support Parkinson research primarily in two ways. As we have done for many years, we provide research grants to beginning scientists with promising, high-caliber research proposals. The proposals selected for funding must have the potential of advancing the state of the science exponentially rather than incrementally. Hence, these proposals are often referred to as being “high-risk/high-yield” ones. Last year we awarded 12 such grants for a total of \$480,000. We also fund research by established scientists from around the world through our Large Grants program and through our Mega Grants program, both of which provide funding in large amounts over periods of up to three years. Last year we provided \$1,661,800 in Large and Mega Grants. All research grants are evaluated by our independent Scientific Advisory Board (SAB) and are subject to strict reporting and accountability requirements.

A second vehicle for the funding of research also serves as the primary vehicle for our funding of comprehensive care and outreach: the network of NPF Centers. As may be seen in the lists reproduced elsewhere in this publication, there are three types of NPF Centers: Centers of Excellence (for research, care, and outreach), Care Centers (for care and outreach), and Outreach Centers (for outreach). Each of these Centers has been so designated following strict scrutiny by our independent Centers Review Board (CRB) and has demonstrated excellence in their respective categories. One year after being designated as an NPF Center, an institution becomes eligible to apply for funding from NPF for research, care, and/or outreach. Last year we awarded 87 Center grants for a total of \$4,783,928.

As this issue of the *Parkinson Report* goes to press, our Board of Directors will be considering the grant recommendations of the SAB and of the CRB for the 2007-08 fiscal year. There were 358 applications for new grants, and the fall issue of the *Parkinson Report* will include a report on all such new grants, together with a brief description of each. All of this information is also made available on our website, www.parkinson.org.

We are proud of the work that NPF does in the fulfillment of our dual mission, and we are most grateful for the continued support of our donors, whose generosity makes that work possible. ■



PAUL F. OREFFICE - Chairman



NATHAN SLEWETT - Chairman Emeritus

The National Parkinson Foundation is pleased to provide this space to our peer organizations to share their messages, events, discoveries, and stories with the entire Parkinson community.

The American Parkinson Disease Association, Inc.

BY: JOEL GERSTEL

Executive Director
Parkinson Plaza
135 Parkinson Ave.
Staten Island, NY



AMERICAN PARKINSON
DISEASE ASSOCIATION INC.

The American Parkinson Disease Association (APDA) is the country's largest grassroots organization. Operating through a network of 57 chapters, 62 Information & Referral (I&R) centers, and 800 support groups across the country, APDA raises awareness, funds research, provides educational materials and programs, and offers support to patients and caregivers with its unique dual mission to "Ease the Burden - Find the Cure."

Easing the Burden - PD patients and their caregivers are the focal point of APDA's mission. Chapters are volunteer organizations that raise awareness through events and funds for research with the proceeds of annual walk-a-thons. At I&R centers, healthcare professionals provide physician and services referrals, educational materials and programs, and support activities for patients and their caregivers. More than \$2.5 million is allotted each year.

Finding the Cure - APDA has been a funding partner in every major scientific breakthrough since its inception 46 years ago. In addition to supporting eight centers for advanced research located in major academic and medical centers across the country, experienced and young scientists annually are awarded research grants and fellowships for promising research. A prominent panel composed of 15 outstanding neurologists and scientists reviews all research applications and recommends funding for those indicating the greatest potential. More than \$30 million has been contributed to research to date.

New APDA Initiatives

National Young Onset Center - APDA introduced the country's first Young Onset Information & Referral (I&R) Center in 1991, in Santa Maria, Calif. Since then, APDA has consistently focused on supporting the young onset population and is now expanding its National Young Onset Center in Glenview, Ill. Julie Sacks, LCSW, is the director, and Michael Rezak, MD, PhD, director of the Movement Disorders Center and Functional Neurosurgery Program at Evanston Northwestern

Healthcare, is serving as medical director. The center's focus is on:

- 1.) Providing innovative educational and outreach programs to young people with PD, their families and healthcare providers.
- 2.) Providing information and resources that will help young people with PD live their lives as fully as possible.
- 3.) Increasing national awareness that PD affects younger people and helping those young people advocate for themselves.
- 4.) Coordinating a national young onset initiative through its Information Line **877-223-3801**, Web site: www.youngparkinsons.org, *Young Parkinson's Newsletter*, and APDA chapters and regional I&R centers.

Veterans Affairs - APDA provides educational materials for the Department of Veterans Affairs' six Parkinson's Disease Research, Education & Clinical Centers (PADRECC) across the country. With the support of a grant from the Medtronic Foundation, APDA's dedicated Armed Forces Veterans' Center in Reno, Nev. is creating a database of I&R centers and support groups for each PADRECC center. The database will assure PADRECC patients and their caregivers current information on the support care available in their areas. ■

Actively Supporting Each Other

BY: IRVING LAYTON

Chapter President
South Palm Beach County Chapter of NPF
Boca Raton, FL

The establishment of the South Palm Beach County Chapter of the National Parkinson Foundation in 2001 brought together a group of people who were not well versed in Parkinson disease. However, in our relatively short existence we have learned and accomplished much.

The goal stated in our Mission is “to give aid, comfort, and support to those persons in our community who are afflicted with Parkinson disease, and their caregivers, and to fund research TO FIND A CURE.”

We believe we are continuing to accomplish our Mission by sponsoring the listed activities below:

1. We have a monthly support/caregiver program which brings in a professional speaker to discuss topics of interest to Parkinsonians. Each session also includes a separate caregiver discussion and an exercise session for those Parkinson patients. These programs are well attended, averaging 35-40 people.
2. We sponsor a bi-yearly Educational Symposium that brings to the community information about new medical procedures, newly approved drugs, and those still in research programs. The speakers are all leading professionals in the field of Parkinson treatment or research. These symposiums have attracted an average of 200 participants.
3. We publish LIFELINES, which is our newsletter, four times a year. It includes not only our chapter activities but also the latest technical information about new drugs and treatments so that our Parkinson community is kept well informed.
4. The members of our South Palm Beach County Chapter work very hard to develop fund-raising programs to fulfill the second part of our Mission – fund research “TO FIND A CURE.” We have established a highly successful Annual Card Party and Luncheon, and annual Golf and Tennis Tournament, and a well-thought-out Tribute card program to honor birthdays, anniversaries, get well wishes, and memorials.



As a result of the success with our various programs in our relatively short existence of 5-6 years, we have increased our fund giving for research “TO FIND A CURE” from \$3000 our first year to \$90,000 this year. To date, our total contribution to research totals \$250,000. We believe this is an extraordinary accomplishment for such a small group.

We have no administrative costs, as all of our Officers and Board of Directors are dedicated volunteers absorbing any costs they originate. Our only costs are for printing and mailing our notices and bulletins. This manner of operation makes more funds available for research grants, and we hold monthly brainstorming meetings to come up with additional ideas to increase our research funding.

We are not resting on our laurels – we hope to continue to increase our yearly commitment to research. The thought and satisfaction in accomplishing this drives us forward to succeed.

We are very thankful and appreciative for the support given to us by the staff of NPF in Miami and especially the help and inspiration shown by Nathan Slewett, Chairman Emeritus NPF. We extend a very personal and special tribute to him. ■

Update on the NPF Mega Grant:

PGC-1 α and Neuroprotection in Parkinson Disease



BY: **BRUCE M. SPIEGELMAN, PhD**

Professor of Cell Biology, Department of Cancer Biology
Dana-Farber Cancer Institute and Harvard Medical School
One Jimmy Fund Way, Smith 958
Boston, MA



In 2007 the National Parkinson Foundation (NPF) awarded a peer-reviewed Mega Grant to Professor Bruce Spiegelman and to Assistant Professor David Simon of the Dana-Farber Cancer Institute and the Beth Israel Deaconess Medical Center in Boston, MA. Mega Grants were given by NPF to only two outstanding investigative teams. These teams competed with top Parkinson researchers from around the world. The Mega Grant concept was designed to invite novel research that could lead to a “breakthrough” in Parkinson disease. Below, we provide the readers of the Parkinson Report an updated summary of their exciting work.

The mitochondria are the “energy factories” of our cells. They make the chemical energy that cells need to function and survive. When the mitochondria don’t work properly, in addition to an impaired ability to generate chemical energy, another consequence is the production of highly damaging molecules called “free radicals” that attack and damage other nearby molecules. This free radical damage is called “oxidative stress” because it results from the production of toxins from oxygen. In Parkinson disease (PD), mitochondrial function is impaired, leading to greatly increased oxidative stress. This oxidative stress is thought to contribute to the progressive loss of specific sets of brain cells in PD. Because of this, strategies to improve mitochondrial function or block oxidative stress might slow or stop the progression of PD.

Based on this hypothesis, an ideal strategy for protecting brain cells in PD would be to both increase mitochondrial activity and also to block oxidative stress. A molecule called “PGC-1 α ” has emerged as a single target capable of both of these functions. When PGC-1 α activity is increased, this leads to the coordinated expression of all other genes

required in order to make new mitochondria. While this action potentially could compensate for the impaired mitochondrial function in PD, a potential problem is that more mitochondria also could mean more free radicals, and therefore increased oxidative stress. However, PGC-1 α has a crucial second activity; it also

“...an ideal strategy for protecting brain cells in PD would be to both increase mitochondrial activity and also to block oxidative stress.”

increases the production of proteins that block the formation of oxidative stress and relieve oxidative stress that pre-exists. Several of these antioxidant proteins individually have been investigated as potential targets for protecting neurons in PD, but PGC-1 α



provides a potential means for upregulating many of these proteins simultaneously. As a result of this dual action on increasing mitochondrial synthesis and increasing antioxidant protein activities, PGC-1 α is highly attractive as a target for protecting brain cells in PD.

Dr. Bruce Spiegelman and colleagues at the Dana Farber Cancer Institute in Boston, the discoverers of PGC-1 α , conducted an initial test of this substance by studying mice that lack PGC-1 α . They exposed these mice to low levels of a toxin (MPTP) that blocks mitochondrial function and is known to cause PD-like disease in both mice and people. These doses caused minimal damage in normal mice. In contrast, the mice lacking PGC-1 α proved to be highly susceptible to death of the same brain cells (“neurons”) that die in PD when exposed to this low dose of MPTP. This showed that normal PGC-1 α activity is important in protecting neurons against this toxin-induced mitochondrial dysfunction. Dr. Spiegelman and colleagues, including Dr. David Simon, next hypothesized that increasing PGC-1 α activity above normal levels would be protective. They initially tested this in different types of cells grown in a dish in the laboratory, and indeed increased PGC-1 α activity did protect the cells from dying when exposed to hydrogen peroxide or paraquat, two chemicals that induced oxidative stress.

For their Mega Project Award, Drs. Spiegelman and Simon have proposed to test the ability of PGC-1 α to protect neurons in mice exposed to MPTP, a chemical that selectively kills the same set of neurons that die in PD (in a region of the brain known as the “substantia nigra”). In order to increase PGC-1 α levels in these neurons, they are taking advantage of the natural ability of certain viruses to carry genetic material into neurons. They are using a virus known as an adeno-associated virus (or “AAV”) modified so that it can infect neurons without harming them and without inducing an immune response. The gene encoding PGC-1 α is inserted into the virus, and then the virus is injected into the substantia nigra, where it enters the neurons, bringing with it the gene for PGC-1 α . This results in elevated levels of PGC-1 α in those neurons. Drs. Spiegelman and Simon and colleagues in their laboratories have been working, with support from the NPF, to optimize the virus in order to allow the maximal level of expression of PGC-1 α following injection in the brain. They will then conduct tests to determine if, as predicted, this protects against the death of substantia nigra neurons following exposure to MPTP. An additional set of studies will involve establishing genetically modified “transgenic” mice that express high levels of PGC-1 α in substantia nigra neurons. These mice are predicted to be relatively resistant to MPTP.

A third aim will be to study the mechanisms by which PGC-1 α increases production of antioxidant proteins, which may lead to the identification of new potential targets for protecting substantia nigra neurons in PD.

If these studies show that increasing PGC-1 α levels in substantia nigra neurons is protective, then this may eventually lead to clinical studies in PD patients to determine if similar strategies can slow the progression of PD. The use of a virus to increase expression of a gene (PGC-1 α in this case) is a form of “gene therapy.” Viruses such as AAV already are being used in early clinical trials in PD patients to deliver other genes, and theoretically may be an option in the future if these studies show that increasing PGC-1 α levels in substantia nigra neurons is beneficial. A limitation of such gene therapy techniques is that they require a surgical method to inject the virus carrying the gene into the brain. However, PGC-1 α is a highly inducible molecule, and it is hoped that eventually agents can be identified that can be used orally to increase PGC-1 α activity without requiring surgical interventions.

The Beth Israel Deaconess Medical Center is also a NPF Center of Excellence (Daniel Tarsy – Medical Director). ■

Five Frequently Asked Questions About Hospitalization

For Patients with Parkinson Disease

BY: **KELVIN L. CHOU, MD**

Brown University

MICHAEL S. OKUN, MD

University of Florida

HUBERT H. FERNANDEZ, MD

University of Florida

DIANE BRESLOW, MSW, LCSW

Northwestern University

JOSEPH H. FRIEDMAN, MD

Brown University

Most people with Parkinson disease will need to be hospitalized at some time. Hospitalization can be stressful for a number of important reasons. The neurologist who takes care of you and manages your Parkinson disease medications may not have privileges at the hospital where you are admitted, and the physicians and nursing staff responsible for your care in the hospital may not know a lot about Parkinson disease. If you need to undergo surgery or other invasive medical procedures, you may not be able to take any medications until the surgery or procedure is complete.

It is important for the patient and the caregiver to plan and anticipate what is likely to happen. This article will answer five of the most frequently asked questions about hospitalization for people with Parkinson disease.

1.) When I am in the hospital, why don't I always get my medications on time?

It is important to realize that hospitals and hospital pharmacies have their own dosing schedules. For example, if a medication is written for “QID” (four times a day), the standard hospital schedule may be 8 AM – 1 PM – 6 PM – 11 PM or some similar variation. A medication written for “TID” (three times a day) may be given at 7 AM – 3 PM – 11 PM or some other standard schedule. Furthermore, many hospitals may have a policy that permits nurses to give medications at times different (generally, one hour before or after) from the scheduled time. This window is provided as a practical compromise because nursing



staffs are busy, and each nurse usually cares for multiple patients. Such a policy provides the nurse time to complete his/her scheduled duties, and provides flexibility in case of emergency on the ward. As a result, patients with Parkinson disease will in most cases receive their medications at seemingly random times.

How can such a situation be remedied? First, make sure that the drug schedule, with specific times, is written into the doctor's orders. For example, if carbidopa/levodopa (Sinemet) is given four times a day, but at 6 AM – 10 AM – 2 PM – 6 PM, make sure that the physician taking care of you knows that it should be given at those specific times. Also make sure that you bring with you the complete list of your medications and the dose of each medication is correct. When you first arrive in your room, talk with your nurse about the importance of receiving your medications on time. Explain that without the medications you can be immobile or uncomfortable and that the medications allow you to move around independently. You may know more about Parkinson disease than the doctor and the staff, and it is your job to help them understand your situation. While you will still need to be somewhat flexible (there are many other important things that may occupy a nurse's time), sharing your knowledge with the staff can alleviate many problems. All hospital staffs want their patients to be well cared for during their stay.



In some cases, patients may be taking medications that are not stocked in the hospital pharmacy. In such situations, the physician taking care of you in the hospital may have to prescribe substitute medications. If you want to take your own medications, you need to bring them from home in their original bottles and give them to the nursing staff. They will then dispense your medications while you are admitted, and there will be no need for substitution. If you are enrolled in an experimental drug protocol, it is even more important that you follow this practice. In some hospitals and outpatient surgical facilities, the doctor can write an order to allow patients to take their own medicines; however, the doses and times must be written in the chart, and the pill ingestion must be supervised and documented.

Pearl: Find out the hospital rule on taking your own medication. Always bring your medications in the original bottles along with a list of the medications, doses, and times of administration.

Pearl: Not everyone in the hospital has experience treating patients with Parkinson disease, so you should share your knowledge and help them understand why you need to take your medications at specific times.

2.) Why can't I take my own medications in the hospital? Why do they substitute some medications for me?



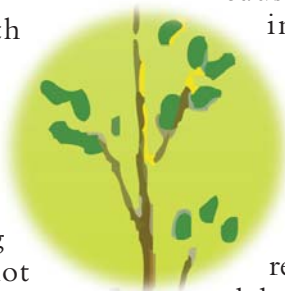
While you are hospitalized, the nursing staff must have control of your medications. This is a safety issue and is standard hospital policy. It is not a reflection of what the staff thinks of you, so don't take it personally.

3.) My mother has Parkinson disease and was recently hospitalized. However, she seems to be moving much worse in the hospital than at home. Why is that?

Several explanations are possible. When patients with Parkinson disease have an infection of some kind, whether it is the common cold, pneumonia, or a urinary tract infection, they often feel like their symptoms worsen. Increased tremor or more difficulty walking may be noted. When the infection is treated and resolves, their symptoms generally return to baseline. Another symptom that may worsen when patients with Parkinson disease have an infection is swallowing. When swallowing is impaired and patients are weak, the food may go down into the lungs, causing an "aspiration pneumonia," which, in turn, may further impair swallowing ability. In these situations, a speech pathology consultation can be useful to formally assess swallowing and make dietary recommendations. In addition, a respiratory therapist consultation for "chest PT" may be helpful. Chest PT consists of several minutes of chest clapping to help mobilize the sputum and make it easier to cough.

Another possibility is the addition of a new medication. Common offenders include antipsychotic drugs or anti-nausea drugs. Haloperidol (Haldol) is a common antipsychotic drug that is used in hospital settings. This drug blocks dopamine receptors and worsens PD. Other commonly used antipsychotics include risperidone (Risperdal), olanzapine (Zyprexa), and aripiprazole (Abilify). The only antipsychotics that can be used safely in PD patients are clozapine (Clozaril) and quetiapine (Seroquel). Common anti-nausea medications that can worsen symptoms of Parkinson disease include prochlorperazine (Compazine), promethazine (Phenergan), and metoclopramide (Reglan). These medications have similar structures to the antipsychotics and should not be used. Trimethobenzamide (Tigan) and ondansetron (Zofran) are suitable alternatives that can be used without fear of worsening symptoms.

Regardless of the cause, all patients with Parkinson disease should be as active as possible while in the hospital. Moving around not only tones muscle, it allows faster recovery and prevents decomposition of the skin, which can happen when staying in one position for too long. Depending upon your condition, however, you may not have a choice as your doctor may order you to bed rest. In that case, physical therapy should be ordered as soon as possible. Some patients may also need rehabilitation at a rehabilitation hospital or a nursing facility before being discharged to home.



Pearl: There are multiple explanations for worsening of Parkinson disease while in the hospital. Infections should be sought and treated. Drugs that block dopamine, like haloperidol and certain anti-nausea drugs, should be avoided. Chest PT, speech pathology, and physical therapy may all be useful in the recovery process.

4.) My husband has Parkinson disease and became confused in the hospital last time he was there. How can I prevent this?

Many things happen in the hospital that can contribute to confusion. Any infection in a patient with Parkinson disease can be enough to tip a patient “over the edge” mentally. Similarly, infections can adversely affect motor function as we discussed above.

The introduction of new medications, especially pain medications, frequently results in disorientation and memory problems. Lack of sleep while in the hospital can also contribute to a confusional state. Continuous alarms from IV machines and hallway lights can all result in frequent awakening. Nurses also may regularly enter the room overnight to take vital signs, give medications, or check on a patient. In some patients, especially in the elderly with intermittent confusion at home, the mere fact that they are placed in a different and unfamiliar environment may tip them into a delirious state. Finally, confusion is commonly seen following a surgical procedure. The combined effects of anesthesia and medications to treat surgical incision pain are contributing factors in this situation.

Confusion will often disappear once the underlying cause is treated, whether it is addressing the infection or withdrawing the offending medications. Diagnostic testing is rarely necessary. Frequent reassurance, support and comfort may be all that is needed to assist the patient through this period. However, sometimes confusion can lead to behavioral problems, such as aggression, refusal to take pills, and even hallucinations or delusions. In these cases, physical restraints are sometimes necessary to prevent self-injury. Some hospitals have bed or wheelchair alarms to alert nurses when patients attempt to wander, while other hospitals may use a sitter to promote safety. If there are psychotic symptoms, such as visual hallucinations, antipsychotics may be used. Remember, in nearly all cases, clozapine (Clozaril) and quetiapine (Seroquel) are the only antipsychotics that should be used in patients with Parkinson disease.

In very severe cases of confusion with hallucinations and behavioral changes, it may be necessary to temporarily discontinue dopamine agonists, MAO inhibitors, amantadine, benzodiazepines, and pain medications if possible. Treatment with carbidopa/levodopa and either clozapine or quetiapine will usually result in improvement. Later, once patients are stable, they may be slowly titrated back onto previous doses if tolerated.

Pearl: Infection and medications are common causes of confusion in the hospital, and when the underlying cause is addressed, problems with confusion usually improve dramatically.

5.) I had deep brain stimulators (DBS) placed two years ago. I now need to have knee replacement surgery. Will the doctors know how to take care of me?

While thousands of patients worldwide have had deep brain stimulation treatment for Parkinson disease and other movement disorders, many medical professionals and hospitals may still not be familiar with this treatment. Many patients with DBS undergo knee replacement surgery, and other procedures without difficulty. However, there are a few things you and your doctors should be aware of. First, if you have had DBS surgery, you can only get an MRI of the brain, and it must be done with something called a head-receive coil. You cannot get an MRI of any other part of the body. This situation exists because the DBS device can become heated and damage the brain tissue during MRI. There are also certain precautions that the radiologists must be aware of while performing a brain MRI. These are available from the FDA. Furthermore, the voltage on your stimulator should be turned down to 0 prior to having an MRI performed. Only an experienced programmer should supervise the procedure. If there is not an experienced member of the DBS team available in the hospital where you are being treated, and/or if the institution is not familiar with performing MRIs in DBS patients, it is probably best not to have the MRI or to wait and have it at an experienced center.

The stimulators can sometimes interfere with the ability to obtain an electrocardiogram (EKG). This test may be important if you happen to have cardiac problems before, during, or after surgery. Therefore, you should bring your portable Medtronic Access Device or Access Review Device (or a magnet that comes with the device) to turn off your stimulator in the hospital. Make sure you know how to turn your stimulators on and off before going to the hospital, and before having any type of surgery. (Again, do not assume that the medical staff will be able to turn them off for you.) Similarly, if you need a brain wave test called an electroencephalogram (EEG),



or will simply be monitored during an inpatient or outpatient procedure, you will need to know how to turn your device off.

If you are undergoing surgery and you have DBS, most anesthetics are safe. However, some precautions need to be taken when using electrocautery. Electrocautery stops bleeding during surgery and could potentially reset your stimulator to its factory settings. As a precaution, only bipolar electrocautery is recommended (with grounding placed below the level of the device). If your neurologist is on staff at the hospital where you are getting surgery, he/she should confirm that your stimulator is on and that the correct settings are reset following surgery. If your neurologist is not at the hospital where you are being operated, you should schedule a follow-up appointment soon after you are discharged from the hospital to recheck your settings.

Pearl: Be aware of what procedures can be done safely with DBS, and be ready to assume primary responsibility for turning it on and off for procedures.

The above tips and scenarios will hopefully aid in minimizing problems for patients with Parkinson disease who are hospitalized. Be aware that, for unclear reasons, some symptoms worsen following general or local anesthesia, and some patients have even reported feeling as if they never return to their baseline. In general, local anesthesia is thought to be safer than general anesthesia, and if you have problems with thinking and memory, they should be evaluated prior to surgery as they may also worsen.

Finally, it is important for you to have discussions with close family members about what you would like to have done in case of a life threatening emergency. They and the medical staff should be aware of your medical wishes. You should choose an advocate who can ask questions and act as your spokesperson. If you have a living will or a durable health care power of attorney, these documents should be brought to the hospital and placed in the medical chart.

On the following pages are two checklists for you to take with you to the hospital: one for you and one for your doctor/nurse. You can play an important role in easing the stress of your hospital stay, which can, in turn, help other patients with Parkinson disease who will follow you.





Information Checklist for Hospital Stays

General Points to be Aware of When Entering the Hospital:

- Provide a list of your medications with exact times, frequencies, and dosages. Be prepared to share your knowledge about Parkinson disease, including on-off fluctuations and the importance of taking medications at specific time intervals.
- Bring medication in original bottles.
- Know which drugs can worsen the symptoms of Parkinson disease.
- Research study participants should provide information explaining the experimental drugs and phone the study coordinator to let them know you are in the hospital.
- Speak up when medications are wearing off.
- Do not take medication on your own. Unless you have prearranged permission, the staff should administer all medication.
- Let the staff know if you have a deep brain stimulation (DBS) implant. Bring the access review or magnet device to turn the stimulator on and off for procedures.
- Contact your neurologist letting him/her know you are in the hospital and give the phone number of your neurologist to your doctor in the hospital.



Be mobile, especially during prolonged stays!

- Walk around as much as possible.
- Inquire about physical therapy or occupational therapy. Even passive range of motion exercises can help prevent contractures if you are not mobile.

If you have difficulty swallowing:

- Sit up while eating.
- Ask for a speech-swallowing therapist.
- Alert staff that your medications may need to be crushed and administered through a tube. Make sure medications are administered one hour prior to meals or feedings, especially if medications are crushed.
- There is a dissolvable form of carbidopa/levodopa called Parcopa® that can be given by placing on the tongue.

Know what factors may make your symptoms worse:

- Failing to get medications at specific times and coordinated with meals.
- Dopamine blocking drugs such as haloperidol (Haldol), risperidone (Risperdal) and olanzapine (Zyprexa) can worsen symptoms. If absolutely necessary because of hallucinations, behavior, or sleep, only quetiapine (Seroquel) or clozapine (Clozaril) should be used.
- Anxiety, stress, and sleep deprivation.
- Urinary tract, lung, or other infections (and antibiotics).

Provide Advance Directives:

Power of attorney for health care and living will. Choose an advocate who can ask questions and act as your spokesperson. Make sure this person is aware of your medical wishes so (s)he can assist in speaking for you if needed.

Information for Your Nurse and Doctor when You Enter the Hospital

Name of your Parkinson disease Neurologist: _____

Phone Number of your Parkinson disease Neurologist: _____

The following are some suggestions to make the hospitalization of this person with Parkinson disease smoother:

- Parkinson disease medications often need to be given at specific times of the day. Therefore, when writing medications in the orders, instead of writing TID or QID, please write specific times (e.g. q8AM, q11AM, etc.).
- Patients with Parkinson disease should resume medications immediately following procedures unless vomiting or severely incapacitated.
- If there is confusion, consider urinary or lung infections. Also consider pain medications or benzodiazepines as a potential cause.



- In cases of prolonged confusion, and an antipsychotic is necessary, quetiapine (Seroquel) and clozapine (Clozaril) are the best options. These two drugs minimally affect symptoms. Avoid using haloperidol (Haldol), risperidone (Risperdal), olanzapine (Zyprexa), aripiprazole (Abilify), and ziprasidone (Geodon).
- If the patient has nausea, please avoid the use of prochlorperazine (Compazine), promethazine (Phenergan), or metoclopramide (Reglan), as they can worsen symptoms. Trimethobenzamide (Tigan) and ondansetron (Zofran) are alternatives that can be used safely.
- Do not mix selegiline or rasagiline (MAO-B inhibitors) with meperidine (Demerol), as it can precipitate a serious reaction characterized by blood pressure fluctuations, respiratory depression, convulsions, malignant hyperthermia, and excitation.
- Do not stop carbidopa/levodopa (Sinemet) abruptly, as this can lead to neuroleptic malignant-like syndrome.
- If medications have to be crushed and administered through a tube, give them at least one hour prior to meals and be aware that CR formulations may not work as well. Protein in meals may interfere with the absorption of carbidopa/levodopa (Sinemet). There is a dissolvable form of carbidopa/levodopa called Parcopa® that may be useful in some patients.
- If you are having trouble getting an EKG, EEG, or using heart rate monitors, consider that the patient may have a deep brain stimulator. You may need to ask the patient or family member to turn the device off to avoid electrical interference. ■



NPF is the Proud Recipient

of a \$250,000 Grant from Medtronic Foundation
to Establish the National Parkinson Care Network (NPCN)

The National Parkinson Care Network (NPCN) will expand service to and improve care for persons living with Parkinson disease (PD) in culturally diverse, socio-economically disadvantaged, and medically underserved communities across the country. The two-pronged program will:

1. Train front-line healthcare providers in the most up-to-date Parkinson-specific treatment and care.
2. Partner with national organizations whose missions are to reach medically underserved populations and that have established national infrastructures for training and/or service delivery. Initial partners include the National Area Health Education Center Organization (NAO-AHEC), the National Association of Community Health Centers (NACHC) and National Alliance for Hispanic Health. Together these organizations reach millions of individuals and families in diverse, rural, and medically underserved communities.

The National Parkinson Care Network is an expansion of Community Partners for Parkinson Care (CPP), a national initiative made possible through two previous grants from the Medtronic Foundation. Since its inception in 2003, CPP has reached more than 3/4 million consumers with information, provided initial training to more than 2300 health care workers, and offered expert opinion on Parkinson topics through media venues. ■

Surviving Adversity

What do a professional golfer, neurologist, acclaimed lawyer, children’s author, nurse, legendary cyclist, former Attorney General, highly respected news anchor, and 20 other men and women have in common?

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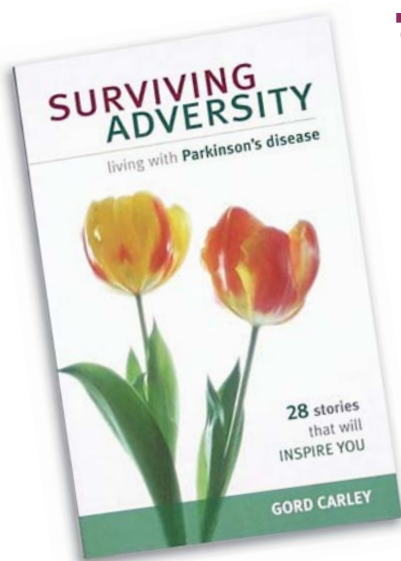
–Elizabeth Mason, living with Parkinson’s disease

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McLean, Virginia

From time to time we print letters that we receive, unsolicited, from readers. The publication of such letters should not be construed to represent the views of the National Parkinson Foundation or of any persons directly associated with it.

Overcoming Pain with Promise

April 3, 2007

Dear Editor:

I have lived with Parkinson's disease for better than ten years now. The National Parkinson Foundation has been a friend to me throughout my journey. Being diagnosed at 32 years of age came with its share of challenges, not the least of which is intense cramping and dystonia.

My morning ritual over time grew into frightening, painful, and consistent episodes. Inevitably, I would find myself on the floor in pain, relying on muscle relaxors, and/or anti-anxiety medications in an attempt to control the episodes. Obviously, both the dystonia and medications were having a significant negative impact on my quality of life.

My doctor, Jeff Bronstein, MD (UCLA), suggested that I participate in a clinical trial for a drug called Apokyn (apomorphine), and I enrolled in the trial. Four years later I am functioning at a higher level than I have been in years. In my experience Apokyn is quick acting and reliable. It bypasses all of the issues that traditional pill forms encounter in the stomach. Being "functional on demand" has afforded me the opportunity to once again enjoy professional productivity and personal growth. I actually appear in a patient information video which I believe you can track down through the Apokyn web site www.apokyn.com.

I'm approaching my 45th birthday. I work full time; I have two teenagers; I ski, play basketball, lecture, and enjoy a very active, full life – even after thirteen years with this disease. Much of the credit belongs to Apokyn, which saved my quality of life.

My family and I thank all of you at the NPF for your efforts in helping patients with Parkinson's disease and their families.

Sincerely,

Bruce Wisnicki
Los Angeles, California

The Power of Your Money

We thank our donors for critical, ongoing support of National Parkinson Foundation's programs and services in research, comprehensive care, and education. Thanks to your philanthropy, NPF will continue to help persons with Parkinson disease and their caregivers live a better quality of life with hope and dignity.

Here are a few examples of what your generosity – and the generosity of thousands of others – makes possible:

Researching the Cause and Cure

Research Grants to a Center of Excellence

NPF awards annual grants of \$50,000 to over \$100,000 to NPF-designated Centers of Excellence worldwide that support innovative, time-limited studies in basic or clinical research in Parkinson disease for up to three years.

Research Grants to Individual Scientists

NPF awards grants of \$40,000 to individual investigators to support bench or clinical research into the causes and cure for Parkinson disease. Priority is given to high-risk, high-yield studies. Competition is keen; there are more than 10 applicants for each grant.

Training Professionals

Allied Team Training for Parkinson (ATTP) is our signature professional training initiative designed to educate physicians, nurses, and allied health practitioners in informed, interdisciplinary care in Parkinson disease. Since its inception in 2003, ATTP has trained 600 professionals and 93 teams who have delivered improved care to 75,000 patients and their families across the country. This year sessions were held in New York City, Phoenix, Florida, and Honolulu.



Professional Coordinators

To achieve the NPF Center of Excellence designation, Centers must conduct research, provide comprehensive interdisciplinary care, and educate the community. They are also required to engage a professionally qualified Coordinator to manage these programs and facilitate patient communication. NPF provides its Centers with grants of up to \$65,000 to support these skilled professionals.

Reaching out into the Community

Young-Onset Parkinson Network Conference

The annual YOPN Conference is the major national symposium for the young-onset Parkinson community, which represents those diagnosed with Parkinson disease before age 50. Your support allows NPF to offer this conference at a modest registration fee to encourage maximum attendance. The 5th Annual YOPN Conference will be held in Chicago July 5-7, 2007 and is expected to attract nearly 400 attendees.

Support to Affiliate Chapters

NPF awards \$10,000 grants to its Affiliate Chapters for projects that advance advocacy, education, or outreach in local communities.

Education and Information

Parkinson Education Guides

This series encompasses the most complete body of literature on all aspects of the disease that is written by experts specifically for persons with Parkinson disease and their families. Each year NPF sends out 200,000 copies of the series, which now includes 10 volumes, 7 of which are translated in Spanish. Each guide is routinely updated and reprinted in runs of 20,000

copies at a modest cost of \$1 per copy. All publications are provided to the public free of charge.



“Ask the Expert” Online Forums

The website: www.parkinson.org is the centerpiece of NPF information services and the most visited website of its kind, receiving 80,000-100,000 visits each month. Special interactive resources include the popular *Ask the Doctor*, *Ask the Surgeon*, and *Ask the Dietician*. These online forums boast 40,000 subscribers. The top ten *Ask the Doctor* questions and answers are reprinted in each quarterly *Parkinson Report*.

The NPF Advantage

NPF's network of 57 Centers, 45 Affiliate Chapters, and 900 Support Groups provide direct comprehensive care and education to hundreds of thousands of persons with Parkinson disease, their caregivers, and families; healthcare providers; and the general public. No other Parkinson organization can boast such broad outreach across the country and around the world. ■

Join the NPF Hope is Golden Campaign Today!



Your donation will support these and many other programs and vital research.

Together, we will fight back and move forward.

Please use the envelope provided or visit www.parkinson.org and click on the **Donate Today link.**

If you would like information on how you can leave a legacy or include NPF in your estate planning, please contact **Rhonda Seriani, Development Director @ 305.243.1061.**



More Questions and Answers About Important Issues in Parkinson Disease

Addressed by NPF's National and International Medical Directors

The National Parkinson Foundation has been blessed with an international network of Centers of Excellence, Care Centers, and Outreach Centers. These Centers touch lives by providing focused and integrated interdisciplinary care for patients, as well as outreach, education, and research. This is the second of a two-part article where we asked our team of experts to address pressing and timely issues about the current and future state of Parkinson disease.

—Michael S. Okun, MD
Medical Director, National Parkinson Foundation

BY: ROGER L. ALBIN, MD, MDS

University of Michigan
Ann Arbor, MI

MICHAEL J. AMINOFF, MD, DSC

Parkinson's Disease Clinic and Research Center
University of California, San Francisco
San Francisco, CA

BASTIAAN R. BLOEM, MD, PhD

Nijmegen Parkinson Center (ParC)
Nijmegen, Netherlands

LAURA S. BOYLAN, MD

Bellevue Center for Parkinson and
Related Movement Disorders
New York, NY

JOHN CAMPBELL, MD

Parkinson Association of Southwest Florida
Naples, FL

THOMAS L. DAVIS, MD

National Parkinson Foundation Center of Excellence
at Vanderbilt University Medical Center
Nashville, TN

OSCAR GERSHNIK, MD

Centro Neurologico, Hospital Frances
Laboratory of Experimental Parkinsonism
Buenos Aires, Argentina

MARK GUTTMAN, MD, FRCPC

Centre for Movement Disorders, Markham Stouffville Hospital
Markham, Ontario, Canada

ROBERT A. HAUSER, MD, MBA

Parkinson's Disease & Movement Disorders Center
University of South Florida
Tampa, FL

ETIENNE HIRSCH, PhD

Universite Pierre et Marie Curie, INSERM
Hopital de la Salpatriere
Paris, France

DOUGLAS E. HOBSON, BSC, MD, FRCPC

The Deer Lodge Centre Movement Disorder Clinic
Winnipeg Regional Health Authority
Winnipeg, Manitoba, Canada

XUEMEI HUANG, MD, PhD

University of North Carolina at Chapel Hill
School of Medicine
Chapel Hill, NC

ROBERT IANSEK, MD

Victorian Comprehensive Parkinson's Program
Victoria, Australia

JOSEPH JANKOVIC, MD

Parkinson's Disease Center & Movement Disorders Clinic
at Baylor College of Medicine
Houston, TX

ANTHONY E. LANG, MD

Toronto Western Hospital Movement Disorders Center
Toronto, Ontario, Canada

MARTHA NANCE, MD

Struthers Parkinson's Center
Golden Valley, MN

RAJESH PAHWA, MD

University of Kansas Medical Center
Kansas City, KS

DAVID K. SIMON, MD, PhD

Beth Israel Deaconess Medical Center
Harvard Institutes of Medicine
Boston, MA

MATTHEW S. STERN, MD

The Parkinson's Disease and Movement Disorders Center
University of Pennsylvania, Pennsylvania Hospital
Philadelphia, PA

LOUIS TAN, MD

Parkinson's Disease and Movement Disorder Centre
National Neuroscience Institute
Singapore

DANIEL TARSY, MD

Parkinson's Disease & Movement Disorders Center
Beth Israel Deaconess Medical Center
Boston, MA

1- What are the limitations of levodopa and dopamine agonists in the treatment of Parkinson disease?

Aminoff: Their benefits decline with advancing disease, and there is no persuasive evidence that they influence the natural history of the disease, i.e., delay its advance.

Hauser: They are helpful, but the big problem is that the disease continues to progress and patients ultimately develop disability due to gait and balance dysfunction, cognitive difficulty or significant fluctuations, and dyskinesias.

Stern: The major limitations of dopaminergic therapies are their inability to treat or prevent PD symptoms that contribute substantially to disability. Dopaminergic therapy not only has well recognized short- and long-term adverse effects, but does little to provide relief for cognitive impairment, depression, loss of postural reflexes, and other “non-dopaminergic symptoms.”

Davis: It is now clear that although these agents greatly improve quality of life and extend life span in patients with PD, they do not effectively treat all symptoms particularly the non-motor aspects (memory loss, urinary problems, blood pressure fluctuations, etc.).

Tarsy: Limitations of dopamine agonists for monotherapy in early PD is that they are less effective than L-dopa and eventually need to be supplemented with L-dopa. Side effects, especially drowsiness and psychiatric effects, often limit their value. Limitations of L-dopa are the increasingly shorter duration of therapeutic action as the disease progresses and motor complications such as dyskinesias and motor fluctuations.

Bloem: Levodopa: Fewer than most doctors and patients believe. The greatest threat to my mind is under-treating in young and active patients who

deserve adequate treatment. For agonists, the greatest threat is dopamine dysregulation syndrome (various addictions).

Huang: Treating non-motor PD patients, treating advanced PD patients.

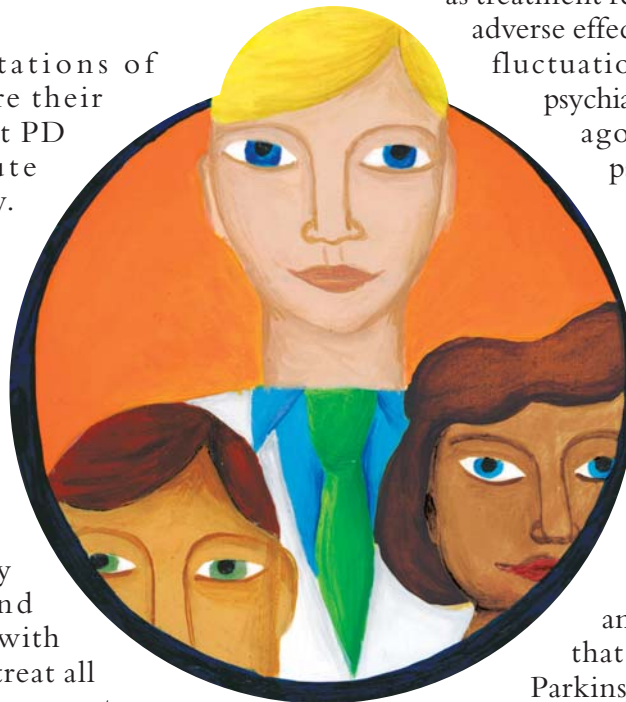
Tan: Targeting on dopaminergic pathways may not be enough, since the non-dopaminergic/non-motor symptoms do not respond well to dopaminergic treatment. In fact, treatment with levodopa and a dopamine agonist is often limited by non-motor side effects that include postural hypotension (low blood pressure on standing up), hallucinations, and memory problems (dementia).

Lang: Limitations include both adverse effects as well as treatment resistant symptoms. Commonest adverse effects with levodopa include motor fluctuations and dyskinesias as well as psychiatric problems later on. Dopamine agonists more commonly cause psychiatric disturbances including “impulse control disorders” (such as pathological gambling) and swelling of the ankles and these drugs tend to be less effective for the symptoms of Parkinson disease than levodopa. Excessive daytime sleepiness can occur with all dopaminergic drugs, probably more commonly with agonists. A major limitation of all dopaminergic therapy (levodopa and dopamine agonists) is the fact that many later-stage symptoms of Parkinson disease are resistant to these therapeutic approaches probably because the symptoms do not relate to dopamine deficiency. These include speech and swallowing problems, freezing of gait, postural instability and falls, blood pressure, bladder and bowel disturbances as well as cognitive decline.

Pahwa: Motor fluctuations and dyskinesia.

No relief with non-motor symptoms.

Nance: Of course, the main limitation is that none of these drugs treats the disease itself, so as the disease worsens, there is a tendency to give higher and higher doses of these drugs to treat the symptoms, and those higher and higher doses are associated with more and more side effects.



Hirsch: Mostly side effects such as dyskinesia and wearing off side effects. In addition this therapy is only active on the symptoms that are a consequence of the dopaminergic lesions. We need much more knowledge about non-dopaminergic lesions (their role in the appearance of the symptoms and ways to restore non-dopaminergic neurotransmission).

Albin: The primary defect is that they have either no effect on or may worsen some of the non-motor features of PD, like hallucinations or orthostatic hypotension.

Simon: Levodopa remains the most effective drug for treating motor symptoms of Parkinson disease. However, as the disease progresses, its duration of effectiveness after each dose becomes shorter, and the risk of dyskinesias increases. Initiating treatment of Parkinson disease with a dopamine agonist (rather than levodopa) is associated with a lower risk of dyskinesias but is a bit less effective than levodopa for treating the motor symptoms of Parkinson disease and carries a higher risk of some side effects such as drowsiness or hallucinations. Any of the dopaminergic agents also carries a risk of increasing compulsive behaviors such as compulsive gambling or hypersexuality.

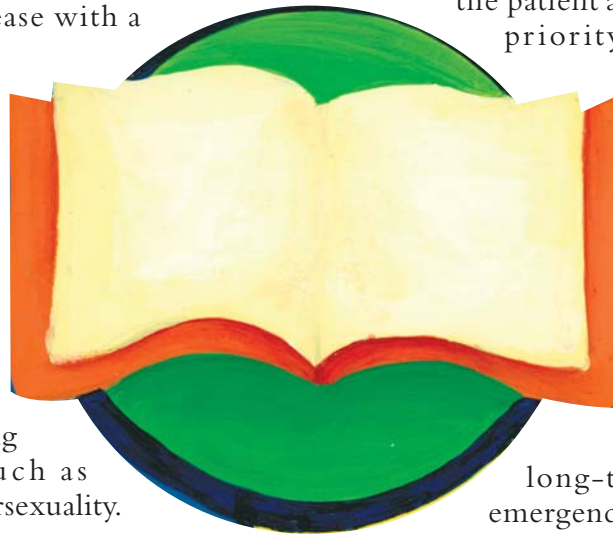
Boylan: Medications lose effectiveness as the disease progresses, and with increased doses, side effects such as abnormal involuntary movements and confusion/psychosis limit their usefulness.

Guttman: Levodopa and dopamine agonists are effective treatments for patients with Parkinson disease. These drugs improve the motor symptoms of slowness and stiffness that are often the most limiting features. Tremor may not be relieved, but since it is usually a rest tremor that goes away with use, it is often not a significant problem. As Parkinson disease progresses, there are a number of problems that may evolve that are not adequately treated with levodopa or dopamine agonist therapy. Some patients develop cognitive changes that do not improve with levodopa and dopamine agonists which may actually make them worse. Balance problems and freezing with walking may also be less responsive to levodopa and agonist

therapy. One of the biggest challenges is when these medications have benefit but are associated with dose-limiting side effects. Patients are very individual in their response; not everyone develops problems. Levodopa therapy may be associated with dyskinesias, wearing off of the benefit after each dose, and sometimes drowsiness. Dopamine agonists, and to a lesser extent levodopa, may be associated with hallucinations and other psychotic symptoms. These tend to occur more often with patients who have advanced Parkinson and who have cognitive change. Dopamine agonists may cause sudden onset of sleep, leg swelling, or impulse control problems including gambling, that limit their usefulness. The dose may need to be reduced or the drug stopped. Often the motor symptoms deteriorate and difficult choices need to be discussed with

the patient and their family as to the highest priority to deal with these difficult situations. Current drug therapy cannot meet all of the needs of Parkinson patients. We do not have treatment to slow the disease progression. Research is ongoing to explore new therapies to achieve this goal.

Jankovic: Although levodopa is clearly the most effective drug for the treatment of motor symptoms of PD, its long-term use is limited because of emergence of complications, particularly wearing off and other motor fluctuations and dyskinesias as well as a variety of psychiatric side effects, particularly hallucinations. The psychiatric side effects also complicate the therapy with dopamine agonists, such as ropinirole and pramipexole. In addition to hallucinations, these drugs can cause a variety of other behavioral effects such as drowsiness and sleep attacks, hypersexuality, and pathological gambling. In our experience ankle swelling is also very common with these drugs. The more traditional dopamine agonists, such as pergolide and bromocriptine, the so-called “ergot” dopamine agonists, have additional risks such as



“Levodopa remains the most effective drug for treating motor symptoms of Parkinson’s disease.”

valvular heart disease and fibrosis of tissues such as the lung, as noted in one of our patients chronically treated with pergolide. When he was switched to pramipexole, the pulmonary fibrosis resolved. The major limitation of the dopaminergic drugs is their inability to improve symptoms that may not be due to dopamine deficit, such as cognitive decline, loss of balance and freezing, autonomic symptoms, and many other non-motor problems.

Gershanik: Levodopa is still the most effective symptomatic therapy for PD. In that regard, dopamine agonists come second in efficacy as they never have shown to be equally potent to levodopa in improving motor symptomatology. In addition, if given initially as monotherapy, they will require levodopa supplementation sooner or later as they tend to lose efficacy with time. That being said, it is clear that these drugs do not directly influence the underlying pathological process or the course of the disease. Moreover, one of the major limitations of both levodopa and dopamine agonists is their lack of efficacy on non-motor symptoms and on those motor symptoms that develop late in the course of the disease (freezing, falls, dysarthria, deglutition disorders, etc.). In addition, the side-effect profile of levodopa and dopamine agonists related to their dopamine receptor stimulation properties is frequently a limiting factor. Excessive daytime sleepiness, hypotension, and psychiatric disorders (both behavioral disturbances and psychotic manifestations) are some of the adverse effects of these drugs encountered in a significant proportion of patients. Levodopa in particular, due to its short half-life, has the tendency to progressively shorten the duration of its effect after each dose, leading to the development of motor fluctuations. As a compounding factor, the pulsatile mode of administration of levodopa is a major causative factor for the development of abnormal involuntary movements (dyskinesia) that, together with motor fluctuations, may significantly limit the functional capacity of the patient. Nevertheless, despite all these limitations, if these drugs are given properly and in due time, according to the needs of the individual patients, they allow us to adequately manage a significant proportion of our PD patients.

Hobson: The main limitation of levodopa and dopamine agonists in the treatment of Parkinson disease really relates to their inability to affect the background progressive deterioration that occurs in

this neurodegenerative disorder. Although they are wonderful early on in controlling the major symptoms, over time they cannot be depended on to provide as smooth a benefit throughout the day, and they also don't address many of the non-motor symptoms of the illness.

“Nevertheless, despite all these limitations, if these drugs are given properly and in due time, according to the needs of the individual patients, they allow us to adequately manage a significant proportion of our PD patients.”

Iansek: The limitations of levodopa are related to a number of factors which include the duration of Parkinson, the limited storage capacity for dopamine in the brain, the age of the individual, and the very short duration of action of the drug. However, taking these factors into consideration, it is very important to be aware that levodopa is a very potent agonist for normalization of mobility in individuals with Parkinson, and therefore, the limitations, in regard to obtaining maximum benefit for any particular individual, are very dependent on the approach, technology, and monitoring mechanisms that take place by the treating neurological team. The development of motor fluctuations does require a specialist team with expert knowledge and the capacity to monitor the outcomes of levodopa adjustments on an hourly basis, or even at shorter intervals, and to have an imaginative approach to the delivery of levodopa in order to overcome some of these shortcomings and limitations. From our own experience we have been able to obtain excellent outcomes with the use of levodopa even in advanced stages of Parkinson by utilizing the multidisciplinary team, intense inpatient monitoring, and adjusting dosages according to the individual's



requirements, as compared to administering medication on an out-patient basis and recommending that the individual or family adjust the medication themselves. “Intensive care” treatment certainly pays dividends in optimizing the limitations of the use of levodopa in order to utilize its tremendous benefit and minimizing its side effects. In our program, the use of hourly administered liquid Sinemet, supported with education and close monitoring, can achieve excellent results and enable people to take control of their lives for many years.

The limitations of dopamine agonists are somewhat different to those of levodopa. The three main factors that limit its benefits are the decreased potency as compared to levodopa and, in most dopamine agonists, a shorter half-life of the medication and the unfortunate high side-effect profile. From my experience the use of the dopamine agonist with a long duration of action (cabergoline) can be very effective in the management of dyskinesia if the dosage is increased up and above recommended levels and its action is augmented by the use of amantadine as an adjuvant drug. However, the high dose and the long term use of the medication unfortunately does result in a high percentage of individuals to experience neuropsychiatric side effects which can impact greatly on the person and the family and that ultimately require the removal of the medication. The use of these drugs in this context does require, again, a multidisciplinary team with an expert knowledge base for all the team members and close monitoring for the detection of side effects and outcomes. It is possible by the use of major tranquillizers to continue high-dose, long-half-life dopamine agonists with benefit and with control of neuropsychiatric side effects.

Campbell: Side effects. Motor fluctuations for levodopa. Behavior problems for agonists.

“In our program, the use of hourly administered liquid Sinemet, supported with education and close monitoring, can achieve excellent results and enable people to take control of their lives for many years.”

2- What would you recommend for a patient diagnosed with Parkinson disease and requiring initial therapy?

Aminoff: Depending on their age and general medical condition, a dopamine agonist such as ropinirole or pramipexole.

Stern: The choice of initial therapy is dependent on the individual patient and there are no cook-book approaches. In general, the approach should maximize control of symptoms, minimize short- and long-term adverse effects and keep the notion of disease modification in mind. For example, a patient with minimal bradykinesia and rigidity might be best approached with an MAO-B inhibitor with the addition of a dopamine agonist and then levodopa as symptoms evolve. A patient with more prominent tremor might require either dopaminergic therapy early, or an anticholinergic (or amantadine). I have a low threshold for initiating symptomatic therapy and have come to believe that better function early in the PD course probably translates into a better long-term course. This may explain some of the positive results seen in both delayed-start trials and the Elldopa study.

Davis: Find a center that is experienced with the diagnosis and treatment of Parkinson disease to confirm the diagnosis (misdiagnosis is common) and help your doctor guide therapy. These centers also frequently provide the opportunity for participation in clinical trials that will help improve our understanding and treatment of PD in the future.

Tarsy: This depends on many individual factors including, firstly, whether any symptomatic therapy is indicated. If it is, as a general practice, I usually use dopamine agonists in relatively younger patients (under age 55) and L-dopa in older patients. Selegiline or rasagiline are alternatives for patients with mild initial symptoms. For tremor predominant PD I consider anticholinergic medications or zonisamide.

Bloem: Whether or not treatment is necessary and what to choose is very much an individual issue, and specific advice cannot be given. But make sure to see a doctor with expertise in Parkinson disease, who has a multidisciplinary team at his or her disposal with at least a Parkinson nurse specialist but, preferably, also a social

worker and an Allied Health team. Always bring your partner or other family members with you, and insist you discuss treatment options without time pressure. Whenever considering treatment, always focus on maintaining your everyday activities as the prime therapeutic goal, not the “cosmetic” suppression of symptoms. And make sure that your life comes first, then Parkinson disease, not the other way around.



Huang: Depending on patient’s age, symptoms, and potential to develop side effects, I use drugs ranging dopamine agonists, levodopa, and MAO-B inhibitors.

Tan: A dopaminergic agent would be recommended. This, of course, is dependent on age, disease severity, functional impairment, and comorbidities. For patients who are old (e.g. more than 70 years) or with multiple comorbidities, levodopa may be started as initial therapy.

“All patients with PD should be on an exercise program and should have specific limiting issues (low voice, incoordination of fine motor skills, etc.) addressed by the appropriate therapist.”

Lang: “Requiring initial therapy” generally means that the symptoms of Parkinson disease are interfering with the patient’s quality of life. Initial therapy can vary depending on the nature of the symptoms and the age of the patient as well as the presence of additional clinical problems. In a young patient with bothersome tremor, an anti-cholinergic drug (e.g. trihexiphenidyl, benztropine) may be sufficient. When slowness and stiffness predominate, other drugs with mild-moderate symptomatic beneficial effects (such as amantadine, selegiline, rasagiline) may provide sufficient benefit. More bothersome or disabling symptoms usually require dopaminergic treatment. In patients under the age of 60–65 an initial trial of a dopamine agonist may provide more-than-adequate benefit (there is some evidence to support the possibility that selegiline and rasagiline may also have neuroprotective effects, but this remains uncertain and a large trial exploring this

potential for rasagiline is currently ongoing). Patients need to be warned about a variety of potential side effects, but one of the emphasized advantages of this approach is the delay of the levodopa with the dyskinesias that commonly complicate this therapy after 3–5 years of exposure. However, if the response is sub-optimal or side effects occur there should be no hesitation to initiate levodopa in disabled younger patients; there are no advantages (and potentially harmful disadvantages) to unnecessarily delaying this treatment. In all older patients or in those with underlying cognitive disturbances the initial dopaminergic treatment should be levodopa.

Pahwa: In general, younger than 70 years, agonists, and older than 70 years, levodopa.

Nance: Many of our newly diagnosed patients are seen through our full-day “Assessment Clinic,” where they meet with physical therapy, occupational therapy, speech therapy, nursing, and social services, as well as the physician, and receive a multifaceted approach to care. All patients with PD should be on an exercise program and should have specific limiting issues (low voice, incoordination of fine motor skills, etc.) addressed by the appropriate therapist. They should have access to educational materials about PD, and be offered a support group or class for “newly diagnosed” patients, so they can meet with others in a similar position. Work or disability issues or caregiver/living situation/psychological issues should be addressed.

As to which medication or medications to use for the motor symptoms of PD, it depends on the patient, his preferences, financial issues, side effects that one particularly wants or doesn’t want to have, what other medications he is on, his age, his perception of his life expectancy and health status, and a host of other issues. I generally use either a dopamine agonist or levodopa, or more recently, rasagiline if the insurers permit. Patients may also need a bowel regimen, counseling or medication for depression, treatment of sleep disturbance and for PD variants such as Lewy body disease, and medications for dementia or hallucinations even before trying a medication for movement problems. Patients may be interested in unproven therapies, such as Coenzyme Q10, multivitamins, Vitamin E, creatine, etc., which should

be discussed carefully. Finally, some clinical research studies target this population and may be desired or desirable for a particular patient.

Hirsch: If the patient is young I would recommend dopaminergic agonists, for an aged patient I would recommend levodopa.

“People have choices of how to spend their money and invest wisely to maximize their returns when they retire. This is similar to the drug management of their Parkinson.”

Albin: Must be individualized. Dopamine agonists are useful, but for many older patients with significant co-morbidities or who are on complicated medical regimens, L-dopa preparations are still the best.

Simon: Most importantly, I recommend a consultation with a neurologist with expertise in movement disorders to discuss the options. There are pros and cons to each of the possible choices, and not all experts agree on which agent is best for each patient. I have generally initiated symptomatic treatment with a dopamine agonist for most patients, particularly young-onset patients, due to concerns about the long-term risk of dyskinesias with levodopa, but may start with levodopa in an elderly patient or if there are signs of dementia. Prescribing habits may change depending on the results of current trials of potential neuroprotective agents.

Boylan: This kind of decision is highly individualized. In most cases, I use levodopa as a first line medication. In the absence of definitive data on benefit for other agents, the ease of use, potency for motor benefit, and relatively few side effects (and low cost) make this a good choice. In individual cases, based on age, severity, and other factors, I may use MAO-I inhibition, dopamine agonists, or other agents.

Guttman: Therapy for Parkinson disease is very individual and each patient should be assessed carefully to determine their best options. I approach initial therapy taking into the account the patient's disability, age, the drug costs, and the target symptom that is most problematic. For patients requiring treatment who are young (under 50), I would consider recommending amantadine if they have tremor, slowness, or stiffness.

Anticholinergic drugs may be useful in young patients if tremor is the most prominent symptom. In patients who are a bit older, I may consider using dopamine agonists as initial therapy. This may help slowness, stiffness, and tremor but may be associated with side effects and higher costs. In the older age group (over 70), or if the patient has considerable disability, I will use levodopa therapy. All of these options are discussed with the patient and their family, and I carefully explain that it is a trial and error process. One drug may work for one individual and not others, so they should not be disappointed if the first choice does not work. I try to create reasonable expectations that the drugs are to improve their quality of life and activities of daily living. We do not expect drugs to completely eliminate all symptoms. I often compare myself to a financial advisor when I discuss options with my patients. People have choices of how to spend their money and invest wisely to maximize their returns when they retire. This is similar to the drug management of their Parkinson. I do not always know the outcome when initiating different therapies, but often accepting some symptoms will allow us to use lower doses of medication or simpler combinations that will reduce side effects, be cheaper, and create more options for the future.

Jankovic: I strongly believe that PD therapy must be individualized and tailored to the needs of a particular patient. Thus, newly diagnosed patients whose symptoms are very mild and do not in any way interfere with their functioning may be started on selegiline, either as an oral tablet or in a form of sublingual preparation (Zelapar) or rasagiline (Azilect). These monoamine oxidase inhibitors may have a mild symptomatic effect but also have been shown to delay the need for levodopa. Additionally, they may delay the development of freezing, one of the most disabling symptoms of PD. In young individuals with early PD who exhibit only mild symptoms, I usually start with dopamine agonists such as ropinirole or pramipexole. In older patients who require symptomatic therapy, I often start with levodopa. Likewise, in young patients whose symptoms clearly interfere with their occupation or with activities of daily living, particularly, if dopamine agonists are not sufficient to control symptoms, levodopa may be introduced early. The selection of therapy and dosages should be optimized, not necessarily to control all symptoms all the time, but to provide a reasonably good quality of life using the mildest drugs at the lowest possible dosage.

Gershanik: It depends on the individual patient, whether young or old, depending on the severity and functional impairment caused by the motor symptomatology, if there is associated depression or not.

Age is, in my view, a determining factor in the choice of either levodopa or dopamine agonists as the first dopaminergic drug. Younger patients tolerate better DA agonists and are the ones at a significant risk of developing motor complications early on in the treatment with levodopa; therefore, I prefer to postpone the use of levodopa in these patients. In mildly affected patients, often I resort to selegiline or amantadine alone or in combination, postponing the need for more potent medications such as DA agonists or levodopa. In older patients, and particularly in those with more severe forms of the disease, there is no reason why we should prevent them from taking levodopa which is, as I said before, the most effective medication available. If depression is present, before adding an antidepressant we should observe the effect of the antiparkinsonian medication on this symptom as often times patients show improvement in their mood with them.

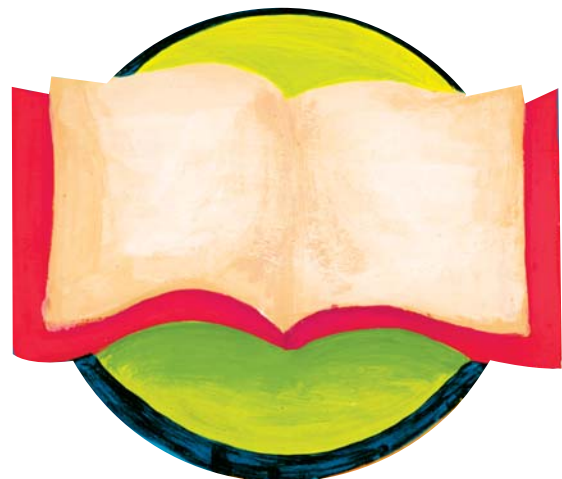
“The selection of therapy and dosages should be optimized, not necessarily to control all symptoms all the time, but to provide a reasonably good quality of life using the mildest drugs at the lowest possible dosage.”

Hobson: From the time of diagnosis, patients can start fighting back through self-education and adherence to an aggressive cardiovascular fitness program. Depending on the age of the patient and the severity of the symptoms, medication such as amantadine, selegiline, and rasagiline may delay the need for some of the more powerful medications. If quality of life is a significant issue though, I would not hesitate in a younger person to initiate dopamine agonists. Typically if patients are over the age of 65, I would recommend initial therapy with levodopa.

Iansek: The newly diagnosed individual with Parkinson requires a special approach. In younger people this can be a devastating diagnosis. Above all else adequate explanation is necessary with a reasonable period of time for people to digest the information and repeated visits to provide back-up responses to any questions that may arise from the initial and subsequent

consultations. This is a very important point in an individual and their family in regard to the long-term approach to Parkinson. It is my experience that people who fail to accept the diagnosis are the ones who find it extremely difficult to manage when the journey becomes more difficult. The lack of acceptance, unfortunately, is followed by lack of involvement and lack of understanding and lack of participation. On the contrary, people who accept the diagnosis are then able to understand the condition better and to participate in their own management and decision making process. In the long term, this makes management much easier and better for the individual. It is, therefore, very important to provide people with the appropriate framework for them to go through this process so that they can emerge having accepted the diagnosis and then be more appropriate partners in the long-term management. If this process is followed, then they are in a better position to decide for themselves what would be appropriate to them once they have been provided with all the appropriate information. It is my general impression that it really does not matter whether levodopa is initiated early or late or whether a dopamine agonist is initiated early or late. Ultimately, people require both medications as time progresses, and it is possible to control symptoms as time passes equally, whichever approach is utilized. There are so many individual aspects for the particular person and their family that it makes it very difficult to recommend one approach or another depending on the individual's needs, their work requirements, their hobbies, their physical capacities, as well as their physical and cognitive capacities.

Campbell: Likely Sinemet. Consider agonist in a younger patient. Azilect is a new option. ■



Sexuality

and Parkinson Disease



BY: **BRONNER GILA, MPH, MSW**

Director of the Sex Therapy Service
Sexual Medicine Center
Sheba Medical Center
ISRAEL



Sexuality

Sexuality is not synonymous with the total experience of our erotic life but contains the basic need for human affection, love, touch, and intimacy. There are various levels of touching: relaxing, healing, soothing, arousing, or sexually stimulating. Besides promoting a strong sense of self-identity, these activities preserve and enhance an individual's self-esteem and are a true confirmation of being alive, loved, and worthy. Couples with sexual problems usually avoid touching one another sexually and non-sexually. One can understand how sexuality may be the origin for happiness and satisfaction, but also it may cause frustration and suffering, thus affecting health and quality of life.

Sexuality and Parkinson Disease

People with Parkinson disease (PwPD) and their partners must cope with major changes in their intimate life and sexual function. Various factors play a role in creating these changes: the disease, the treatments, and the general consequences of a chronic illness (e.g. fatigue, stress, or depression). Age-related sexual changes and myths about sexuality and Parkinson disease also contribute to the high prevalence of sexual disturbances in PwPD.

Motor symptoms (e.g. rigidity, tremor, and bradykinesia), mood changes (depression), treatment with anti-parkinsonian medications and antidepressants, and social changes (unemployment) may result in sexual difficulties. Depression contributes to low sexual desire, erectile dysfunction, reduced lubrication, and difficulties to reach orgasm. The medications may also induce mood and libido changes, erectile dysfunction, and inhibited orgasm. Many people with PD feel that physical disability interferes with their normal sexual habits. The masked face can be interpreted by their partners as lack of sexual interest.

The bradykinesia and rigidity cause them to become more passive thus imposing a more active role on the healthy partner. Tremor and sleep disturbances cause many couples to sleep in separate beds or bedrooms, and thus this leads to decreased opportunities for intimate touch. Thus PwPD may refrain from making sexual advances or initiating intimate touch due to fear of rejection by their partners or due to failure.

Our Clinical Experience

We offer sex counseling services to patients and their spouses in order to promote the intimate experience and improve their quality of life. It's important to treat both partners, since male sexual function and female sexual function mutually influence each other. For example, when a man has erectile dysfunction, there is a high probability that his spouse will experience sexual dysfunction (e.g. painful intercourse or inability to reach orgasm). Interestingly, when the man is successfully treated for his erectile dysfunction, there is a significant improvement in his spouse's sexual functioning.

Our approach for treating sexual problems is based on a multidisciplinary team and cooperation with other specialists (urologist, gynecologist, psychiatrist, neurologist).

The sexual counseling is comprised of the “Intercourse–Outercourse” approach, which offers each couple a special training based on the concept of sexual flexibility and open communication.

The Intercourse–Outercourse training enables flexible options. Each couple can have intercourse as they did previously, with the assistance of the sex therapist or the physician (e.g. providing a medication for erectile dysfunction with appropriate counseling to increase success rates). Couples can choose outercourse, which means that they can enjoy a

variety of pleasuring sexual activities without penetration of the penis into the vagina. Outercourse enables people with limitations and disabilities to remain intimately active. Hugging, caressing, kissing, or holding one another increases intimacy and self-esteem and contributes to couples’ quality of life. They practice various kinds of pleasuring touch using proper aids to overcome their limitations (e.g. using body oil enables a smooth massage when the movement of the hands is rigid). Together, we explore each partner’s preferences and let them practice intimately at home. Those who wish to proceed with sexual stimulation may use outercourse to reach orgasm by oral or manual stimulation. Outercourse enables each partner to choose the desired level of pleasure and enjoyment. The open sexual communication enables couples

to share their feelings and thoughts in a way that most of them have never experienced.

We believe that in spite of their disabilities, people with PD are still sexual persons with the ability to share love, bonding, intimacy, and sexual experiences. Therefore, the Sexual Medicine Center in Israel offers professional training. We have to take into consideration the fact that physicians, nurses, social workers, and other health care providers find it difficult to address sexual issues as a natural part of their clinic routine. The combination of sexual life deterioration along the course of Parkinson disease and the difficulty to discuss sexual issues emphasizes the increased need for our professional assistance. ■



The Parkinson's Disease and Movement Disorders Center

of the University of Pennsylvania Health System

BY: **SUZANNE REICHWEIN, BASW**

Program Coordinator
The Parkinson's Disease and Movement Disorders Center
University of Pennsylvania Health System
Philadelphia, PA

A Pioneer in Parkinson's Disease Care

In 1982, Howard Hurtig and Matthew Stern, neurologists at the University of Pennsylvania, had a vision... to create a comprehensive Parkinson's disease center at Graduate Hospital, an affiliate of the University. Aided by an enthusiastic nurse, Gwyn Melvin Vernon, a Center was born. The Parkinson's Disease and Movement Disorders Center (PD&MDC) has a rich history of evolving to meet the needs of patients. With a mission of providing excellent care, education, and support, and participating in significant research, the Center has flourished. As the numbers of patients grew, more clinicians were added to the team. In 1994, Amy Colcher joined the staff after completing a fellowship and currently heads the Huntington's Disease Center. Andrew Siderowf became a member of the team in 1998, bringing an expertise in clinical research to the group. In 2002, Stacy Horn, who trained at Rush University in Chicago, rounded out the practice with a holistic approach to the management of PD. The staff of the Center has an amazing record of longevity with the average length of tenure being 14 years.

The PD&MDC has been active in the community over the years. Initially, there were 5 support groups in the area. This number grew to 39 with new groups forming every year. Recently, a newly diagnosed group was started, and a DBS support group is planned for the fall. The Center was one of the few to have a dedicated social worker, Jane Wright, MSW, who was instrumental in providing care to many patients who needed resources in the community as well as forging a relationship with the Parkinson Council, the local NPF chapter. The Council, composed of people with PD and family members, is a major supporter of the PD&MDC. In 1992,



FOUNDERS OF PD&MDC, H. HURTIG,
M. STERN, AND G. MELVIN-VERNON, 1982

the Center joined forces with the NPF becoming one of the first Centers of Excellence. In 1996, with the sale of Graduate imminent, the Center was offered a new home at Pennsylvania Hospital, America's first hospital (1751). With the additional space at the Penn Neurological Institute, the PD&MDC created a specialized physical therapy program for PD and movement disorders. With the support of Dan Aaron, one of the founders of Comcast and a PD patient, the Dan Aaron Parkinson's Rehabilitation Center opened in 2000. Heather Cianci, a dynamic Physical Therapist, took on the challenge of developing the program. Heather worked as a one-person operation until the volume grew and additional staff was needed.

One of the latest initiatives of the PD&MDC is the Psychological Services Program. The Center is fortunate to have Sandy Fritsch, PhD,

as a resource. Sandy, a family therapist, was diagnosed with PD in 1996. Blending professional expertise with personal experience, Sandy reached out to patients. Seeing the devastation that neurobehavioral problems cause in individuals and families, she created a counseling program with the support of the Aaron Foundation and the NPF. Referrals from neurologists outside of the Center are common, making the program accessible to all PD patients in the community. The counseling is tailored to meet the needs of the individual or family; some may need only one session to recover their coping skills, whereas others may need time to work out complex issues.

Research has been a key component to the mission of the PD&MDC. The Center has an expansive program in experimental therapeutics. The Brain Bank, in existence since 1985, and other collaborative research with the Center for Neurodegenerative

Disease Research at the University of Pennsylvania have contributed to advances in the understanding of the basic mechanisms of neurodegeneration in PD and related disorders. The latest innovative project is a study of pre-clinical diagnosis of Parkinson's disease. The Parkinson Associated Risk Syndrome Study (PARS) is a novel study seeking ways to detect pre-symptomatic patients. With support from the Parkinson Council, a successful pilot was launched to collect data on individuals. As a result, Drs. Stern and Siderowf, in collaboration with investigators from the Institute of Neurodegeneration, designed a multi-center protocol in which 15 centers from around the country are taking part. This ambitious project will screen 7500 first-degree relatives of PD patients who will then enter a 2-year longitudinal study. The objectives are to estimate the frequency of olfactory (sense of smell) loss in first-degree relatives as

compared to those that have no deficit. The ultimate goal of PARS is to test the feasibility of identifying a cohort of at-risk individuals and ultimately conduct a clinical trial of PD delay or prevention. In March 2007, the CNDR and PD&MDC received the Morris K. Udall Center designation from the National Institutes of Health (John Trojanowski PI) to investigate cognitive abnormalities in PD and in experimental animals. Drs. Hurtig and Siderowf will direct the clinical projects.

Twenty-five years has brought a great deal of change and growth to the PD&MDC. These are exciting times because, with the great increase in interest and research into the mechanisms of how PD starts and progresses, there is greater hope that major breakthroughs are on the horizon. The PD&MDC is committed to remaining on the forefront of the battle to solve the riddle of PD. ■



PD&MDC STAFF, 2007

The Top 10 Questions and Answers from NPF's Ask the Doctor Forum



MICHAEL S. OKUN, MD



HUBERT H. FERNANDEZ, MD



KELLY D. FOOTE, MD



RAMON L. RODRIGUEZ, MD

We are pleased to present this month's Ask the Doctor questions and answers. The National Parkinson Foundation (NPF) has recently upgraded and relaunched the Ask the Expert Forums online at www.parkinson.org. For those of you who may be unaware of this free service, the Ask the Expert Forums allow patients, caregivers, doctors, students, and others interested in Parkinson to log on and have all of their questions answered. Additionally, readers can browse other questions and answers, and add to the existing discussion. The NPF forums are unique, and over the years they have been expanded to include Ask the Doctor, Ask the Surgical Team, Ask the Parkinson Dietician, Ask the Spanish Doctor, Talk to a Speech Clinician, and several unmoderated forums including a Caregiver Forum, a Young Onset Parkinson Disease Forum, and a Chat Room. From anywhere on this planet, you can log on and the NPF forums will be available to help with the motor, non-motor, and quality of life issues surrounding Parkinson disease. We are pleased to present the top ten questions from this month.



Q. Frozen

My Dad in India has become completely frozen, all of a sudden his whole body became stiff and he is unable to speak or move and he is bedridden. He was very good a month ago. Before he was taking:

- 1 Sinemet 4 times a day
- Ropark 2mg 3 times a day
- Seroquel 225mg/day

Because of hallucinations he had to stop taking Ropark and recently he changed his dose to:

- 2 Sinemet 3 times a day
- 1 mg Mirapex 3 times a day

What could be the reason for him to become a "vegetable" all of a sudden? I am unable to see him like this; please help.

A. It is hard to offer specifics without an in-person examination; however, a few things must be immediately considered:

- 1- Infection, especially urinary.
- 2- Underdosed or improper medications. He may need levodopa without an agonist and perhaps levodopa combined with a drug like Seroquel or Clozaril that may eliminate or limit hallucinations/behavioral problems. The medicines must be given at frequent doses and intervals depending on his individual need for them.
- 3- Watch out for other medical conditions (anemia, cancer, diabetes, etc.).
- 4- Make sure your doctor performs a full physical and neurological examination.

Sometimes slight changes in environment or general health can result in worsening. Also, remember other drugs may result in confusion and side effects (beyond the Parkinson drugs).

Q. Help Sleeping at Night

My young onset person with Parkinson (20 yrs with PD, now age 53) has trouble falling asleep at night and/or awakening too early in the a.m.

What is the safest med to take? Is there a danger in using Nyquil? Ambien? He is on Trazadone and Sinemet CR and Clonazepam.

He sleeps easily during the day. Right now he has a lot on his mind with family problems which may be a factor. He addresses these with his psychologist. There is restlessness at night.

A. For early morning awakenings and "a lot on the mind" I start with a psychiatric interview, and consider an antidepressant. In some cases I even refer to a psychiatrist.

Because of your story and the two meds you mention (which help sleep), I would have a low threshold for a sleep study. He may be suffering from a treatable condition like sleep apnea.

I usually push doses of one sleep medicine before adding another. Seroquel has also been helpful for some patients. All of these medicines can cause confusion and I would be careful in adding multiple medicines at the same time.

If he is found to have RLS, or restless legs syndrome, then from the RLS standpoint, Sinemet may not be the best drug. Its duration of action is so short that it can cause augmentation and rebound RLS (meaning the RLS symptoms get worse

and they are experienced sooner and earlier during the evening or day). Be aware that late doses of agonists in PD often result in sleep problems.

Dopamine agonists (such as Requip or Mirapex) taken at night are probably the best medications for RLS. If this does not work, there is Clonazepam, Neurontin, or opiates.



Q. Extreme Difficulty Walking

I am getting very concerned lately about my walking. I have PD and I am 56 years of age. When my husband and I go to Church, movies, etc. and I sit for more than an hour and get up to walk, I have a very difficult time getting up, but my largest concern is my legs do not want to work. My husband hangs on to me because my legs are dragging and I am walking at a turtle's pace. I use my cane, but that does not help either. That happens for about 10 minutes or more and then I can start walking without my husband having to hold me from falling. It is still slow moving. This happens mainly later in the afternoon but also in the morning if we have to go out. I am on a very low dose of Requip. After using just that little bit of muscle to walk and I sit, my right side starts to have really bad tremors and then I fall asleep. Is this normal for PD or do I need to have more medication? My doctor wants me to try Stalevo. He has seen me when I cannot walk and having the really bad tremors on my right side after just making a fist. He said I have very little dopamine and need to be on more medication. What is your opinion? I really like my doctor, and I want to see if you are on the same page as he is. Thank you.

A. I agree you seem undermedicated, and your early morning and late day symptoms support that notion. You need medication doses spread throughout the day probably at at least 5-hour intervals. I usually either titrate up agonists or add Sinemet before using Stalevo, but Stalevo, which is a combination of Sinemet and Comtan, may also work. You and your doctor will need to be sure that your walking problems are Sinemet responsive, and also consider physical therapy and assistive devices.

Q. Social/Behavioral Changes

My dad is 83 years old and has PD. We have been asked by his assisted living facility to move him because some of his behavior is causing problems with other residents. He seems to be almost singularly focused on masturbating – both in private and in public areas. It has escalated more recently, although he has had this issue for a number of years. He does suffer from some hallucinations too.

He is on a number of medications, and I feel like maybe the medications are contributing to the behavior issues. I read something about hypersexuality and wonder whether reducing some of the meds might mollify the behavior. He is currently on:

- Ropinirole (Requip) 4mg 3x/day
- Carbidopa/Levo 25/100 4x/day
- Comtan 200mg 4x/day
- Aricept 10mg 1x/day

The onsite psychiatrist also has him on:

- Seroquel 25mg 3x/day
- Premarin .90mg 1x/day

He is otherwise in good physical health.

This is my first participation on a forum for PD.

A. We have seen this in a number of patients with PD. We usually stop the Comtan and the Requip (dopamine agonists) which could be contributing to the behavioral issues. We will also typically manage with levodopa plus Seroquel or Clozaril, and I notice Seroquel is being used already (may need to adjust the dose and frequency of Seroquel or Clozaril). Hang in there. This does occasionally happen and it isn't your fault.

In summary, a medication adjustment may be helpful, as may be seeing a specialist and sometimes a counselor or psychologist is also helpful.



Q. China Stem Cells

In China at the Beijing Tiantan Puhua Hospital, they are performing stem cell surgery for Parkinson. They use the hRPE cells extracted from the retina. Since this is only approved in clinical trials in the U.S.A., I'm considering going to China

and having the surgery done. I would appreciate any comments, negative or positive, from you on this procedure. Thank you.

A. Before undergoing a procedure like this, I recommend you look hard at the evidence. There is no strong evidence currently supporting the use of stem cell therapy in human PD patients. We are not quite there yet in terms of our understanding of human stem cells to be performing surgical procedures on humans. There is, however, a dopamine cell replacement therapy which uses the retinal-cell-generated dopamine. It is in trial and it is called Spheramine, and that is a clinical trial you may apply to be part of in the US.



Q. Vision and Parkinson

I am very interested in knowing more about PD and vision. My husband, who has had PD for over 28 years, continues to have blurry vision and to see double in spite of recent cataract surgery with correction for astigmatism that left his vision at 20/20 and 20/40. In the last two years he has seen 3 ophthalmologists, 1 neuro-ophthalmologist and a retinologist, all of whom say that his eyes are healthy, but they don't seem to have answers for the blurry and/or double vision. We gather the vision problems are caused by PD and we are beginning to wonder if he will ever be able to read and watch TV comfortably again.

Can you give any insight (no pun) into the problem?

A. Visual acuity is usually not impaired tremendously in PD, although sometimes seeing contrast in color is affected. What is most commonly impaired is the ability of the eyes to work together. What may happen is that the person with PD develops what is called convergence insufficiency, and this leads to double vision particularly when things are closer to the eyes. Solutions may include prisms, and holding books and things further from the eyes.

There are many other causes of visual problems, and therefore, I always recommend a neuro-ophthalmological examination like you have already pursued.

Q. What does Azilect do for Parkinson Patients?

My husband's Dr. just prescribed Azilect (.5 gradual to 1.0 mg) on top of Sinemet 25/250 and Comtan 200mg. What is the new med supposed to do to help PD?

And thanks so much for your help on this web site!!!

A. Azilect is an MAO-B inhibitor. It blocks an enzyme in the body that makes dopamine more available, and therefore, it helps with dopamine responsive symptoms in PD (may help with tremor, stiffness, slowness, etc.). The studies show it may add 1-2 hours of "on time," but in some patients they may not notice a difference. The neuroprotective benefits remain unproven; however, in a recent trial there was some preliminary evidence it may have a disease-modifying effect.



Q. Is three-times-a-day dosing enough to justify DBS?

I am a 75-year-old male diagnosed with PD in 1994 currently taking Sinemet CR three times a day along with Mirapex packs 1mg three times a day. Supplementing this with 25/100 Sinemet when needed. I'm experiencing the typical PD symptoms such as freezing, balance problems, various pains in various places, especially in the mornings, which I attribute to stiffness. People tell me I'm doing well considering the length of time I've had this disease. I don't feel that I'm doing that well because the disease is progressing and my ON times are decreasing as the OFF times are increasing. Some days it seems that I'm spending the whole day in some degree of discomfort and general slowness of motions.

I have a neurologist that has been watching me for about one year and he recently said that I'm a candidate for DBS. I saw a neurosurgeon twice in this past year and, like an automobile going to a mechanic for repairs, I did not show much of the symptoms. Consequently, the

neurosurgeon is not impressed by my symptoms and states that I may be disappointed because the results may not be as dramatic as I may expect. The neurosurgeon also states that the greatest effect of this DBS is in tremors of the hands and arms. I have minor tremors in my hands and arms. My difficulty is in pain and stiffness, slow motions, balance, etc. which seem to be connected to the body rather than the extremities.

What is your opinion of this?

A. Be careful. Taking medications three times a day is not appropriate for a medication trial in a potential DBS patient. You need more intervals and more combinations of medications. Only symptoms that respond to medications will respond to surgery and you need medication optimization as a first step.

Next you will need a full multidisciplinary team and an on/off UPDRS PD scale after optimization of medications. DBS is complex and you may or may not be a candidate.

You mention many symptoms that may be managed medically, and I would suggest you seek out a movement disorders neurologist to discuss management options before proceeding toward surgery.

Finally, DBS in the right candidate may help many more symptoms than just tremor.

You may want to visit www.parkinson.org and download the free book on DBS and look particularly at expectations so that you may understand the limitations of this therapy.



Q. Is there a better target for DBS?

I have idiopathic PD and have treated it with conventional medications for 16 years. I am still dopamine responsive, but I experience unpredictable "on-off" fluctuations when fully medicated. I am planning to have a bilateral DBS "package" installed this summer. Would I be wise to seek out a neurosurgeon who is willing to target the zona incerta (cZI) or other target rather than the subthalamic nucleus?

A. Great question. Hold the phone! There are small series of patients published with DBS utilizing other brain targets beyond STN and GPi. The zona incerta is a target that has been recently utilized more for tremor, but may also eventually emerge as a PD target; however, we do not know the profile of patients for which this target may be appropriate.

I would suggest at this point using STN or GPi DBS, which are proven and FDA approved, unless you decide to enroll in a surgical clinical trial.

This potential target around the zona incerta may be the same fiber bundle we target for STN and GPi. Cameron McIntyre at Cleveland clinic have done great work modeling this region and many targets may actually be stimulating similar connections – all roads may connect.

Finally, there is an emerging DBS target called the PPN that may be useful for people with gait and balance problems in PD. More trials will be needed of this and the other targets.



Q. (For Spanish Speakers – From Ask the Spanish Doctor)

Quisiera saber si la paroxetina (Paxil) puede influir en los estados Off-On del Parkinson. Mi madre toma Paxil 20mg una vez al día. Hace dos días se le acabó el medicamento y no se lo tomó en la mañana. Ese día estuvo en Off el día completo, pero al siguiente día se tomó la paroxetina y estuvo mucho mejor. ¿Es ésto una coincidencia, o tiene una explicación científica?

MP

A. MP, lo más probable es que esta observación sea una coincidencia.

No hay evidencia de que el Paxil tenga algún efecto en los síntomas motores del Parkinson. Como toda enfermedad, y aún en personas sin ninguna enfermedad, hay días buenos y otros no tan buenos. Lo más importante es que su mamá se tome los medicamentos todos los días y evite cualquier lapso. ■

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National Parkinson Foundation

Literature/ Information Request

The National Parkinson Foundation offers many informational resources free of charge. You can access and download the following publications through our website, www.parkinson.org, or you may use this form to make your request and send it to us using the envelope attached inside this issue.



IN ENGLISH:

- ___ NPF Brochure: Your Guide to Parkinson Disease
- ___ NPF Brochure: Should You Volunteer?
- ___ PD Research Studies
- ___ NPF Annual Report
- ___ Parkinson Report (Quarterly)
- ___ Patient Request Card
- ___ Medical Alert Card

PATIENT EDUCATION MANUALS:

- ___ What You and Your Family Should Know
- ___ Medications
- ___ Fitness Counts
- ___ Nutrition Matters
- ___ Speech and Swallowing
- ___ Caring and Coping
- ___ Practical Pointers
- ___ Mind, Mood and Memory
- ___ Guide to Deep Brain Stimulation Therapy

EN ESPAÑOL:

- ___ Lo Que Usted y Su Familia Deben Saber
- ___ Medicamentos para la Enfermedad de Parkinson
- ___ Estar En Forma Cuenta
- ___ La Importancia de la Nutrición
- ___ Dificultades con el Habla y la Deglución (tragar)
- ___ El Cuidado y la Adaptación Necesaria
- ___ Consejos Prácticos

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CHECK ONE: PATIENT CAREGIVER FAMILY MEMBER OTHER HOW LONG? _____

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PREGÚNTELE AL MÉDICO

Ramon L. Rodriguez, MD contesta preguntas médicas con respecto a la enfermedad de Parkinson y a materias relacionadas.

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1501 N.W. 9th Avenue/Bob Hope Road
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