

Summer 2010

PARKINSON'S DISEASE, LEWY BODIES AND DEMENTIA

By J. Eric Ahlskog, PhD, MD

Parkinson's disease (PD) is notoriously linked to the substantia nigra, the brain region that degenerates in this disorder. The substantia nigra connects with another brain site, the striatum, and transmits signals by release of the neurotransmitter, dopamine. This loss of the substantia-nigra-striatal dopamine circuit is fundamental to treatment of PD. Thus, the primary medications used to treat PD replenish brain dopamine.

Among people with PD, the degenerating substantia nigra contains "inclusions" in affected brain cells.

These inclusions, which are small lumps of discarded cellular products, can only be seen with a microscope, using special stains. These PD inclusions are called Lewy bodies, named after the German physician who first saw them in 1912. Lewy bodies are generally thought to be the hallmark of PD and confirm the diagnosis post-mortem.

The classic PD symptoms of slowness, tremor, stiffness and walking problems often improve dramatically with levodopa and other forms of dopamine replacement therapy. These drugs restore dopamine function in the striatum.

That discovery four decades ago focused researchers on the dopaminergic substantia nigra as central to our thinking about PD. However, with effective treatment

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APDA REHAB RESOURCE CENTER



Dr. Terry Ellis, director of APDA Parkinson's Rehabilitation Resource Center at Boston University's Sargent College, answers a caller's question about his exercise program. The center, which is the only one of its kind providing PD patients free physical therapy and exercise information, has received more than 300 inquiries since it was introduced this year. (See page 12 or visit www.apdaparkinson.org for information.)

APDA CENTER MEDICAL DIRECTOR AN AUTHOR OF NEW DBS FINDINGS

Jeff Bronstein, MD, PhD, APDA's UCLA Information & Referral center medical director, was an author of the June 3, 2010 New England Journal of Medicine article reporting that deep brain stimulation in either of two commonly used sites is equally effective in improving motor symptoms and improving quality of life.

The study, co-sponsored by the Department of Veterans Affairs (VA) and the National Institute of Neurological Disorders and Stroke, took place at six VA hospitals and included 299 patients who were randomly assigned to undergo either pallidal stimulation or sub-

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PRESIDENT'S MESSAGE

Dear Reader:

The other day I heard a “good news – bad news” report about not-for-profit organizations’ donations during the past year. The bad news was that they are down by 3 percent from last year; the good news was that it was less than the 5 percent decline that occurred during the 1970’s recession.

It reminded me of a friend who has what he calls “my hangnail syndrome,” which basically says don’t tell someone with a minor pain that he is fortunate that it isn’t a major pain. Pain is pain, and when it is yours, it is major.

There are few individuals or organizations that are not still feeling the pain of our economic downturn of the past few years. It is beyond annoyance; it is heart-level pain when people are losing homes, postponing retirement and rationing their health care. It is equally challenging when organizations are forced to eliminate programs and funding that are central to their missions.

We at APDA recognize our own “good news – bad news” situation as well. It is no secret that these are not the best of times, but we continue to maintain the standards of service and support that have made us the largest organization of its kind in the United States. APDA receives no governmental or public funds. Pharmaceuticals and other traditional funding sources have cut back drastically, and we are more dependent than ever upon the income of our chapters and centers, and the donations of generous individuals.

In half a century there are certain to be lean and fat years. We have weathered lean years before and will no doubt do so again. By staying focused on our mission, however, and adjusting when need to do more with less, we will meet them, too. The challenge is not to believe that the fat years are the norm, but rather an opportunity to prepare for the leaner ones.



President Miele, second from left, with 2010 Esposito Award recipients, Vermont Chapter president Michael O'Connor, left, and Debbie Guyer, St. Louis coordinator, and board member Mario Esposito, Jr. at APDA's annual conference last month. The awards recognize outstanding service to people with PD.

We are grateful for all support, and we pledge to continue to meet previous research commitment and fund new research at the level possible, which right now are our nine centers for advanced research and medical student fellowships. Our national network of chapters and patient support centers continues to provide information, educational materials and programs, physician and services referrals, and raise awareness. And, we continue to introduce new programs such as our e-newsletter, monthly helpful tips, rehabilitation resource center, caregiver program and “Have a Question About PD” services. (See our Web site www.apdaparkinson.org for information on all these services or call 800-223-2732.)

A handwritten signature in black ink, appearing to read "Joel A. Miele Sr.".

Joel A. Miele Sr., PE
President

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Materials concerning Parkinson's disease research and answers to readers' questions are solely for information and should not be used for treatment purposes, but for discussion with the patient's health care provider.

Q: I am having difficulty sleeping at night. Is this a symptom of PD? What can I do?

A: Sleep difficulties are very frequent in Parkinson's disease (PD) and have various causes that may need specific treatment.

It is important to try to identify the origin of the sleep problems to treat them adequately. Here are examples of situations associated with sleep disruption:

1. Depression and anxiety
2. Frequent need to urinate during the night
3. Discomfort because of Parkinson's symptoms such as stiffness and tremor
4. Arthritis and other musculoskeletal pain
5. Side effects of some medications including anti-parkinson medications
6. Post-nasal drip or accumulation of secretions in the throat
7. REM behavior disorder where the patients become agitated during dreams and can hurt themselves
8. Excessive daytime sleepiness; it can be caused by some medications or by a reversal of the sleep/wake cycle
9. Restless leg syndrome

Sometimes the cause of the sleep problem is difficult to identify and patients may benefit from a sleep study or a referral to a sleep clinic. Finally, it may not be possible to find a cause except for the Parkinson's disease, and a mild sleep medication may be prescribed.

Q: My ophthalmologist recommended cataract surgery? Is this a safe procedure for a person with Parkinson's disease and, if so, what precautions should I take?

A: Cataract surgery is safe and widely performed in people with PD. It is very important to bring a list of all your medications to your visit with the eye surgeon. The list must include even your vitamins and over-the-counter medications. The surgeon may want you to stop certain medications that increase your risk of bleeding, such as aspirin, before the surgery. Other medications for enlarged prostate such as Flomax can cause complications during the surgery.

You may be instructed not to eat or drink anything 12 hours before the procedure. Ask the surgeon if you can take your PD medications with a sip of water the day of the surgery, so you can be comfortable, and not have too much tremor. This is usually allowed.



MARIE-HELENE SAINT HILAIRE, MD
Associate Professor of Neurology, Boston University School of Medicine and member of APDA's Scientific Advisory Board

The procedure is performed in an outpatient setting, under local anesthesia and usually lasts less than one hour. Oral or intravenous sedation can be used to reduce anxiety, or if the person with PD expects that the tremor or dyskinesia would prevent him/her from lying still.

Cataract surgery is a safe and effective way to restore vision when cataracts impair enjoying activities such as reading or traveling.

Q: Are there any tests to diagnose Parkinson's disease?

A: At this point in time, a diagnosis of PD is based on clinical history and an examination performed by an experienced neurologist.

At the visit, the neurologist reviews the symptoms reported by the patient, the family history, and the past medical history. He or she looks at the list of the medications to eliminate other causes for the symptoms. During the physical examination, the physician looks not only for the typical signs of PD (tremor, stiffness, slowness) but also for other signs that are not compatible with PD and may lead to another diagnosis.

When the history and examination fit the typical profile of PD, usually no other test is necessary. Tests are only performed when the presentation is not typical or when the diagnosis is not clear-cut. They include brain

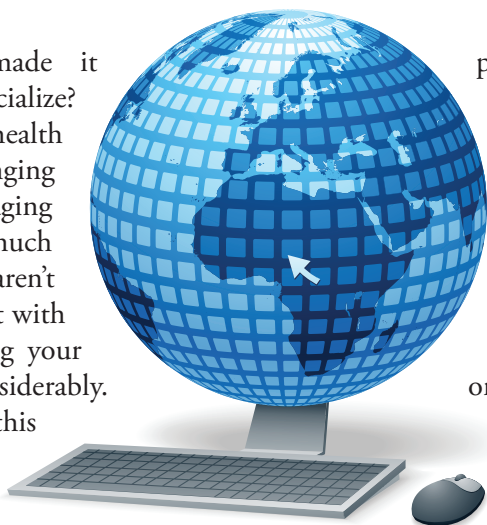
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THE WORLD AT YOUR FINGERTIPS

By John Amber

“When the wind of change blows, some build walls – others build windmills” - Chinese proverb

Has Parkinson's disease made it increasingly difficult for you to socialize? If so, it's probably justified. Your health may be making it more challenging for you to get around, and managing your affairs may be taking so much time and energy that there just aren't enough hours to maintain contact with all the people you know, making your once active social life dwindle considerably. You can, however, change this dramatically with the help from a tool people use every day – the computer.



Many older persons who have not used a computer are intimidated at first, but as evidenced by the introduction of Medicare D, computer-based communications are the new normal. Take it one feature at a time, utilize free available help – especially young people in your circle – and you'll wonder how you did without one all this time.

A computer can open up your world and connect you with information, resources, ideas and friends – new and from the past. It can also put you in touch with people from all parts of the globe. If you don't have a computer your local library does and some offer free lessons, although you may need to reserve a computer in advance or register for specific courses.

Some basics:

- The most dynamic element of the computer world is the Internet. Web sites are the backbone of the Internet because this is where you can get a world of information, from online newspapers, encyclopedias, reference guides, finances, recipes and movies. APDA has many helpful Web sites. Go to our main site www.apdaparkinson.org and from here you can access many Parkinson's resources including your local APDA chapter and Information & Referral center. One of the most beneficial Internet tools is communication, which can be done in a variety of ways including e-mail, message boards, forums, chat rooms and social media. E-mail works much like regular mail where

people write letters. The main difference is that e-mail gets delivered much faster than traditional mail, usually within a matter of seconds, and no stamp is needed.

- Message boards are much as they sound. A common area is used for people to leave messages for one another. Forums are similar, but usually focus on a particular topic. Many Parkinson's disease forums exist on the Internet. A couple of these include www.healthboards.com, www.topix.com/forum/health/parkinsons-disease, and there are many others.

- Social media is one of the newest phenomena on the Internet. Facebook, which is the most popular, enables people to have free Web site pages all about themselves. Here you can have pictures, information and video all about you. Many long-lost friendships have been reacquainted from people finding one another on Facebook.

- A more immediate method of communicating is through chat rooms. These are Web sites in which you can have conversations with the many different people who are online at the same time. Although, instead of speaking your words you type them, and the exchange of information goes back and forth similar to a conversation. There are literally hundreds of chat rooms, many of which are centered on a theme (finances, travel, computers, personals, senior citizens, etc.) Many Parkinson's chat rooms are available including: www.wemove.org, www.parkinsonsrecovery.net, www.healingwell.com/parkinsons.

With the computer you will find a whole new social circle that you didn't have before and didn't even know existed. So do take advantage, and you'll see that the world is at your fingertips.

John Amber is APDA's associate director for the West Coast.

APDA'S VETERANS' CENTER PROVIDES UPDATES

• **President Signs Caregivers Bill:** President Barack Obama has signed S. 1963 (The Caregiver's Bill) into law. The new law creates a support program for veteran's caregivers that will provide training, financial assistance, and improved respite service. The law also improves health care services for America's women veterans, expands the mental health services provided by the Department of Veterans Affairs (VA), and expands supportive services for homeless veterans. Details can be found at <http://Thomas.loc.gov/cgi-bin/bdquery/z?d111:S1963:/>

• **VA Benefits Guide Now Available:** The VA's 2010

guide to "Federal Benefits for Veterans, Dependents, and Survivors" is now available online at http://www1.va.gov/opa/publications/benefits_books.asp.

• **Foster Homes for Veterans:** VA's Medical Foster Home



program finds a caregiver in the community who is willing to provide a veteran with 24-hour

supervision and personal assistance. This would be a long-term commitment where the veteran may live for the remainder of his/her life. Veterans who enter the Medical Foster Home all meet nursing home criteria. The veteran pays the caregiver \$1,200 to \$2,500 per month to provide this care which includes room and board, 24-hour supervision, assistance with medications, and any personal care. For more information visit www1.va.gov/geriatrics/medical_foster_home.asp

Information for this column is supplied by APDA's Veterans Information & Referral Center, Reno, Nev., 888-838-6256 ext. 1715. For more information visit www.reno.va.gov/parkinsons/parkinsons.asp.

NEW INDEPENDENT RESOURCE FOR STEM CELL INFORMATION

Stem cell research holds tremendous promise for treatment of many diseases, but there are organizations preying on patients' hopes – often for large sums of money – for conditions including PD where current science does not support their benefit or safety.

In response to the growing number of aggressive marketing

campaigns offering stem cell treatment, the International Society for Stem Cell Research (ISSCR) has launched a Web site to arm patients, their families and doctors with information they need to make decisions about stem cell treatments.

ISSCR, an independent, nonprofit organization promoting

and offering information relating to stem cells, established the site to provide existing internationally accepted medical criteria concerning clinics worldwide.

The site includes a page to submit a clinic for review, and another discussing the "Top 10 Things to Know About Stem Cell Treatments." Go to www.closerlookatstemcells.org.

AAN Issues Guidelines for Nonmotor PD Symptoms

The American Academy of Neurology (AAN) has issued a new guideline recommending the most effective treatment to help people with sleep, constipation and sexual problems, which are common but often under-recognized PD symptoms.

Erectile dysfunction is a common sexual problem for men with PD. According to the guideline, the drug sildenafil citrate may improve this condition.

The drug isosmotic macrogol is suggested for

constipation, another common PD symptoms.

For problems with excessive daytime sleepiness, the guideline recommends that doctors consider the drug modafinil to help people feel more awake. It is important, however, to note that one study showed that people taking modafinil have a false sense of alertness, which might pose a safety risk for activities such as driving. The guideline also found the drug methylphenidate may help with fatigue.

WHAT ARE INSTITUTIONAL REVIEW BOARDS AND WHY DO WE NEED THEM

By Abdallah Geara, MD

IN the second half of the 20th century, the American government established a set of rules and regulations to protect individuals agreeing to enroll in medical research. These rules were influenced by prior errors and misconducts. Most of these misconducts happened at the end of the 19th century and the start of the 20th century:

- In 1892, Albert Neisser, a professor of dermatology at University of Breslau, while trying to discover a vaccine for syphilis, inoculated four healthy children and three adolescent prostitutes with serum from patients known to have syphilis.

- In 1932, the US Public Health Service started a Public Health Service syphilis study later known as "The Tuskegee Syphilis Study." The study included 600 African-American males from rural Alabama with a high incidence of syphilis infection; they were monitored for 40 years. Subjects were not told about their disease. Even though penicillin had become the standard treatment for syphilis in 1947, the study continued until 1972, and the participants and their families were denied treatment.

The ethical issues involved in the Tuskegee syphilis experiment heightened awareness of the need to protect humans. The governmental investigation led to the Belmont Report (1979) and the federal regulation requiring Institutional Review Boards (IRB) for protection of subjects in studies involving human subjects.

- During the Second World War, the Nazi medical experiments in concentration camps included: infecting groups of prisoners with viruses to observe the course of the disease, testing poison bullets to find more effective ways of killing, testing prisoners under high-altitude conditions of low air pressure and lack of oxygen to see how long they could remain alive. The trial of these doctors in an American court led to "The Nuremberg Code," a 10-point section in the final verdict detailing the limitations on the use of humans in experiments.

- In the late 1950s, 12,000 babies were born with severe deformities because of thalidomide that was prescribed to control sleep and nausea throughout

pregnancy. The drug was not FDA approved and experimental.

- In 1964, the World Medical Association defined the rules for medical research in the "Declaration of Helsinki". It is the basis for Good Clinical Practices used today. The most important points: (1) research with humans should be based on laboratory and animal experimentation, (2) research protocols should be reviewed by an independent committee, (3) informed consent is necessary, (4) research should be conducted by medically/scientifically qualified individuals and (5) risks should not exceed benefits.

Currently, according to federal law, all proposed human research projects must be reviewed by an IRB before approval. IRBs are committees at academic institutions and medical facilities to monitor research studies involving human participants.

The composition of these committees differs among institutions, but all IRBs should fulfill these rules: (1) at least five members, (2) sufficient diversity of members (gender, race, cultural background, and professional expertise), (3) at least one member not affiliated with the institution.

The approval of a research protocol is granted if the
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Flower Power for Parkinson's

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

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

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

Share this offer with friends and family and help Parkinson's research even more. The price per bag, \$29.95, includes all shipping and handling charges. Orders must be received by October 1, 2010.

Two ways to order:

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

TulipWorld guarantees the quality of its bulbs and growing all responsibility for delivery. Packages will be sent in October.

Fresh flowers every day.

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APDA
TO SAVE
THE MOVING
TO THE CURE

PLANNING IS THE ROADMAP TO HAPPY TRAVELING

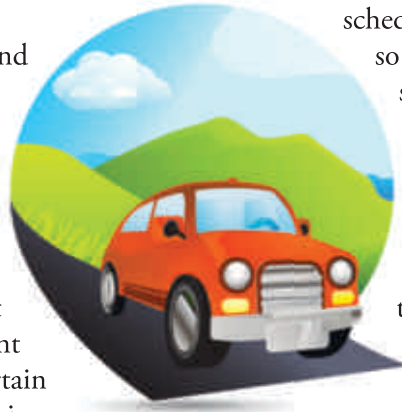
Peggy van Hulsteyn compares an airport experience with purgatory – the noise, the long waits and rude people and finally being treated like a drug lord as personnel rifled through her Parkinson's meds.

Summer is the time most people think about vacations and Peggy and many other people with PD favor the roadways over the airways.

Shelly Peterman Schwarz agrees and offers the following when on the road:

1. Take along your personal "Disabled" windshield card, which is honored in most states including on rental cars and vehicles in which you are a passenger. She advises that you contact the police department in your destination city to be certain of local ordinances. She also advises to carry a copy of your doctor's letter certifying your condition, which can be used at the local motor vehicle office for a temporary permit should you lose or misplace the original.
2. Keep an extra outfit in the car in case you spill something on your clothing and need a quick change.
3. Take along a U-shaped inflatable neck pillow to prevent getting a stiff neck on long drives.
4. Include the following items that can really save the day:
 - a collapsible cup and drinking straws
 - cellophane tape

- paper clips
- Ziploc bags in different sizes
- extra pair of eyeglasses and wrist watch
- small flashlight (with new batteries)
- calculator



Vacations, unfortunately, don't include escapes from medications, and staying on your medication schedule is as important away as it is at home, so be certain that you have enough (plus some backup) with you. Also take along copies of your prescriptions should the unexpected happen and you are without.

Peggy also suggests that you think of the journey itself as the destination and enjoy the whole trip. Drive slower and stop at sites that catch your eye. Take more breaks and exercise to hold off stiffness and revitalize your body and mind.

She also advises a pre-trip meeting with traveling companions to make certain that they understand that you may not be able to keep up with them. Be honest about your limitations and needs and assert that they are not arbitrary or negotiable.

For other health tips online, subscribe to APDA's e-newsletter on www.apdaparkinson.org and click on the e-Updates button on the right side of the home page.

This article was compiled from Peggy van Hulsteyn's article, "Traveling Smarter, Not Harder: Tips on Traveling with a Chronic Disease," and Shelly Peterman Schwarz's book, "Parkinson's Disease: 300 Tips for Making Life Easier."

ASK THE DOCTOR

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MRI (to rule out other options such as strokes or normal pressure hydrocephalus), certain blood tests (including heavy metals like copper or genetic tests), and though rarely chosen, PET or SPECT scans to evaluate the activity of dopamine cells in the brain.

Other clinical features that help support the PD diagnosis are clear improvement with the medication carbidopa/levodopa and occurrence of abnormal

involuntary movements (dyskinesia) after being on the medication for a few years. However, these features are only useful later in the course of the disease.

Despite these limitations, studies have shown that a movement disorder neurologist is 90 percent accurate when making a PD diagnosis. Nevertheless, we need to find better ways to diagnose PD, and several studies looking for biomarkers in PD patients are under way.

APDA AT WORK AROUND THE COUNTRY

Fundraising successes don't need to be glitzy galas or complicated competitions, as recently proven by three Mississippi teenagers and a support group network.

In Mississippi

For retired Brig. Gen. Uriel B Padgett, the call to war would beckon years after his 37 years of service in the U.S. Army National Guard. In 1996, after slight tremors and difficulty moving his leg, he was diagnosed with Parkinson's disease. The disease progressed slowly over the years, stealing small bits of mobility from the former Special Forces paratrooper. Today, each day is a new battle.

In March, as APDA's Mississippi Chapter prepared for its inaugural "Moving To Find A Cure" 5K race along the reservoir in his hometown of Brandon, Padgett discovered he had his own set of troops, including a team of special forces.

Just four days before the event, his granddaughters, Alisha Kennedy and Jana Padgett, heard about it and knew they had to participate. Alisha wrote a short story about Padgett and posted it, along with a photograph, on a Web site that allows donors to give online, and posted the link on Facebook asking people to donate or participate in the walk. Other family members did the same, and in three days the girls raised more than \$500 and recruited their cousin Misty Pruitt.

On Saturday morning, the girls donned T-shirts that read "Papaw's Little Dolls" across the back and pinned a photo of their "Papaw" on the front. (His grandchildren know him as "Papaw," and he calls his granddaughters

"little dolls.") "We wanted people to know who we were and to give a face to people in our community struggling with PD. The girls had a great time at the race, enjoyed the beautiful walk across the causeway and joked with the fishermen in boats lining the banks. In total, they raised \$625.

Alisha reported that her grandfather told people about the race, the Web site and the forum that followed at the YMCA for weeks afterward. "It was a much-needed boost because he has really struggled this last year."

In Florida

On the West Coast of Florida, APDA's affiliated support groups reached out to their local contacts and put together a fully donated "Vacation Getaway" that included two round-trip tickets to the winner's choice of a destination served by AirTran, a two-night stay in a Marriott Hotel, and \$1,000 in spending money. A mail campaign of a personal letter from one of its members with PD by each group asking for a \$10 donation to be eligible to win the vacation package resulted in \$7,000 for PD research.

Young Onset Activities

All six New England chapters and Information & Referral centers have combined their collective talent and energies for the New England Regional Young Onset Parkinson's Retreat, Sept. 12-13 at Fairlee, Vt. The family-oriented program features speakers, exercise, dancing, craft activities and an opportunity to enjoy the outdoor attractions at beautiful Lake Morey Resort, which offers golf, formal gardens, hiking trails and water sports. Information is available by calling 888-763-3366.

APDA's National Young Onset Center and the National Parkinson Foundation join the Northwest Georgia Parkinson Disease Association and APDA's Information & Referral Center at Emory University for the Southeastern Parkinson Disease Conference, Oct. 15-17. The event at Atlanta's Sheraton Gateway Hotel promises education, support and advocacy and includes lectures addressing numerous PD topics that affect older as well as young onset participants ...several of which will be Web cast. Additional information is available on www.youngparkinsons.org or calling 877-223-3801.



Brig. Gen. Padgett's granddaughters, Jana and Misty Padgett and Alisha Kennedy, stand for uniform inspection before the Mississippi Chapter's inaugural "Moving to Find a Cure" race.

RESILIENCE IS A PROCESS THAT ANYONE CAN BUILD

By Linda O'Connor, LCSW

Hearing the words, "You have PD," is a life-changing event that sends people (both the diagnosed person and family members) on a journey full of challenges and uncertainty. How you react, adapt, and continue with life can make all the difference in how you feel emotionally, cope, and handle your relationships. The quality of adapting well in the face of struggle is called resilience.

Resilience involves finding life meaningful despite adversity. It is the capacity to bounce back, feeling strengthened and more resourceful.

Resilience is not a trait that people either have or don't have but a process involving behaviors, thoughts and actions that can be developed and strengthened. No matter what your age, life circumstances, or PD symptoms, you can build your resilience to weather life's challenges. Following are 10 ways to build resilience:

- **Make connections.** People with social support do better emotionally and physically.
- **Make achievable goals.** Make them small and realistic. Figure out what you can change and of what you need to let go.
- **Take action.** Action on your goals gives the

sense of accomplishment and capability that feels good.

- **Locate your strengths.** Everyone has them. How did you overcome challenges in the past? What skills did you use?
- **Express gratitude.** It reminds you that something is good and changes your focus.
- **Maintain hope.** Give yourself permission to be hopeful.
- **Keep things in perspective.** Avoid blowing things out of proportion. Focus on what you can do rather than what you can't.
- **Utilize your faith/spirituality.** Having a connection to a community of faith can bring comfort and peace.
- **Give to others.** Attend a support group, volunteer with an APDA chapter, get involved.
- **Humor works.** Laugh at the silly things in life; find the humor in struggle. It really does lighten the load. Take an example from APDA Arizona Chapter president and Parkinson's rapper Sharon Kha on YouTube.com.

Ms. O'Connor is APDA's Information & Referral Center coordinator at Cedar-Sinai Medical Center, Los Angeles. This article appeared in the center's spring 2010 newsletter.

What are Institutional Review Boards and Why Do We Need Them?

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project fulfills all the ethical criteria: Risks to subjects are minimal, selection of subjects is equitable, informed consent is available, the privacy of subjects is conserved and the project involves a monitoring to ensure the safety of the subjects. The approval is usually given for six to 12 months. The investigator must submit a renewal request at the end of this period. At the termination of the study, the investigators should report all adverse effects.

What is an informed consent?

When an investigator is approaching a patient for inclusion in a medical research project, he/she is required to get informed consent. Informed consent is a process that should include several steps: (1) the investigator must explain the purpose of the study, (2) all the steps of the projects must be explained including all risk and

benefits, (3) the investigator must report any conflict of interests if present and (4) the investigator must make certain that the subject understood all the details before signature.

The most important parts of the informed consent that are not usually stressed is that the subject has the right to withdraw from the study whenever he/she wants, his/her non-approval will not affect medical care and he/she can contact the IRB to report any non-ethical conduct by the investigator (the contact information of the approving IRB must be written in the consent form).

Dr. Geara is a member of the Richmond County (N.Y.) Medical Society and an internal medicine resident at Staten Island University Hospital.

Parkinson's Disease, Lewy Bodies and Dementia

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of these movement problems in the early years of PD, other symptoms developing later in the course became increasingly apparent to PD clinicians. Most notably this includes thinking and memory problems, which may surface in advancing PD; when severe, these fall into the category of dementia. Dementia is defined as a general loss of intellectual abilities.

The substrate for this late-developing intellectual decline among PD patients was debated for many years. However, there is now consensus opinion that this reflects more widespread Lewy neurodegeneration, which fits with the well-known Braak staging scheme for PD. In other words, among PD patients who later become demented, Lewy bodies are found not only in the substantia nigra and neighboring regions, but also at higher brain levels, including the intellectual centers of the brain cortex. This clinical condition is referred to "Parkinson's disease – dementia" or PDD. The prevalence of dementia in PD clinics or in community-based studies may be as high as approximately one-third.

Age plays a major contributory role in PDD. Normal aging in the general population is associated with brain atrophy on MRI brain scans; at least slight memory impairment is common among the otherwise normal aged. Moreover, the likelihood of all forms of dementia increases

with advanced age. The risk of PDD likewise becomes more likely in late life. Conversely, the risk of dementia is markedly less in younger-onset PD patients, at least until they eventually reach advanced ages.

The most common cause of dementia in the general population is Alzheimer's disease, which is fundamentally different from PDD. However, the second leading cause of dementia in the general population is Lewy body dementia; this bears great similarity to PDD.

In Lewy body dementia, patients develop intellectual impairment as an initial presenting feature. Typically, this is associated with parkinsonism, which may occur simultaneously, or sometime later in the course of Lewy body dementia.

Like PDD, Lewy body dementia may also be associated with hallucinations and problems of bladder, bowel and low blood pressure (reflecting involvement of the autonomic nervous system). Thus, fully developed Lewy body dementia is clinically almost identical to PDD. Moreover, both conditions have very similar brain neuropathology, with wide-spread Lewy body proliferation, including the brain cortex. The difference in the time-course of symptoms is the primary distinguishing feature between these two conditions. Hence, PD investigators have distinguished these with a simple rule:

Parkinson's disease dementia (PDD): parkinsonism precedes intellectual decline by more than a year (usually much longer).

Lewy body dementia: dementia either occurs first or within a year of parkinsonism.

This distinguishing rule is a bit arbitrary, representing consensus option, but useful to clearly define cases for research purposes.

Treatment of the intellectual impairment in PDD (or Lewy body dementia) is limited to medications that increase brain levels of acetylcholine; this is a brain neurotransmitter important in cerebral memory circuits. Such medications include rivastigmine, donepezil and galantamine, which are mildly helpful, but not dramatically effective.

Hallucinations may occur in PDD and different medication strategies are used for those problems (however, hallucinations sometimes also occur in PD without dementia).

One major research goal is identifying a strategy to prevent PD progression beyond treatable motor symptoms. On a microscopic level, the focus must be on limiting spread of the Lewy neurodegenerative process.

Dr. Ahlskog is a professor of neurology at the Mayo Clinic, Rochester, Minn.

NIH-Funded Survey Studies PD Patients Barriers to Mental Health Care

The National Institutes of Health (NIH) is funding a survey study that may be used to develop new strategies to improve access to and quality of mental health care for people with Parkinson's disease.

Dr. Roseanne Dobkin, assistant professor of psychiatry at UMDNJ-Robert Wood Johnson Medical School, Piscataway, N.J., is conducting the national survey

to understand better PD patients' difficulties using the mental health care system. The anonymous survey will take participants approximately 15-30 minutes to complete online, over the telephone, or on paper.

A history of mental health treatment is not required for participation. Additional information is available from Dr. Dobkin at 732-235-4051.

NEW YOUNG ONSET WEB SITE HELPING PEOPLE OF ALL AGES

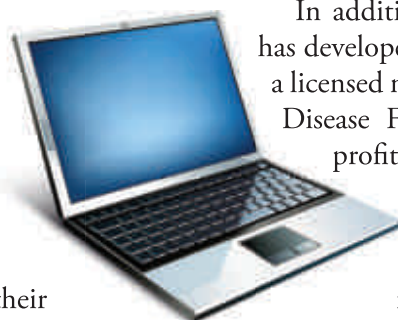
By Julie Sacks, MSW, LCSW

APDA's National Young Onset Center is having a busy and exciting summer. July is the culmination of a yearlong project to enhance the structure and content of the Center's Web site.

The project's original goal was to develop an interactive resource guide that would include a directory of no-cost or low-cost programs and services that would provide young people and their families with some direction as they negotiated the medical, psychological, and financial aspects of young onset PD. While the resource guide focuses on some categories specifically of interest to younger people with Parkinson's such as employment, accommodations, and parenting, it also includes many general resources that will be helpful to people of all ages.

We are proud to be able to present the Parkinson's community with this kind of resource. It not only fulfills a need now but also was created to grow and change over time. We are counting on site visitors to make this directory their own by adding resource reviews and recommendations through the Share Your Opinions

feedback option.



In addition to the resource guide, the Center has developed a partnership with Paul Short, PhD a licensed neuropsychologist, with the Parkinson's Disease Family Service Organization (a non-profit serving Maryland). Dr. Short has a great deal of insight into the ways PD and YOPD affect the person with the disease and the entire family, and he will offer this perspective through the site's new blog.

All of the content has a brand new layout/design with a more user-friendly navigation system. Take some time to visit our Web site this summer. We will continue to add new information and, perhaps most importantly, share what we learn from you—those things that help you live well and stay strong.

Visit the APDA National Young Onset Center Web site at: www.youngparkinsons.org, or call us at 877.223.3801.

Ms. Sacks is APDA's National Young Onset Center director.

APDA Center Medical Director an Author of New DBS Findings

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thalamic stimulation. The conclusion that patients with PD had similar improvement in motor function after either pallidal or subthalamic stimulation was surprising because PD experts had believed that stimulation of the subthalamic nucleus was more effective than the globus

pallidus interna area.

Dr. Bronstein is also a member of APDA's Center for Advanced Research at UCLA, and the director of the VA's Southwest Parkinson's Disease Research, Education and Clinical Center.

Survey Indicates Neurologists Delaying Levodopa Therapy

While levodopa remains the gold-standard treatment for PD, a recent survey of physicians indicates that almost half increasingly intend to delay initiating its use, particularly in young patients.

"Treatment Algorithms in Parkinson's Disease," conducted by Decisions Resources, a research and advisory firm for pharmaceutical and health care issues, reported that responding neurologists said that they are "very likely" or "likely" to postpone initially prescribing levodopa, citing that treatment over time can lead to motor fluctuations, dyskinesia and reduced responsiveness to the medication that all PD patients

ultimately receive.

The report noted that compared to primary care physicians, neurologists less frequently use levodopa as first-line therapy for patients with mild PD under the age of 65, and are increasingly using dopamine agonists and MAO-B inhibitors to manage mild motor symptoms, delaying the need for levodopa.

Primary care physicians responded that it is "very likely" or "likely" they will increase the use of dopamine agonists and/or MAO-B inhibitors when initiating levodopa therapy in order to reduce the needed dosage.

Educational Material & Patient Support Resources

APDA is the source of a variety of free educational and patient/caregiver support materials. Most publications listed below can be downloaded from the Web site, www.apdaparkinson.org, publications page. Single copies are available by writing to the national office or calling 800-223-2732, faxing to 718-981-4399, or contacting any of the APDA Information & Referral Centers throughout the United States.

Free subscription to a monthly e-newsletter and "Tip of the Month" feature are available on APDA's Web site home page. Lotsa Helping Hands, a private, caregiving coordination service that allows family, friends, neighbors and colleagues to create an online community to assist a caregiver with daily tasks can be reached by clicking the "Ease the Burden" button.

APDA's National Resource Center for Rehabilitation provides direct telephone (888-606-1688) and email (rehab@bu.edu) access to a licensed physical therapist at Boston University's College of Health and Rehabilitation Sciences: Sargent College, to answer questions about exercise, provide information about programs in the caller's area and provide educational materials.



BOOKLETS

(order by letter)

- A.** Parkinson's Disease Handbook
- B.** Young Parkinson's Handbook
- C.** Be Active
- D.** Be Independent
- E.** Speaking Effectively
- F.** Good Nutrition
- G.** Aquatic Exercise for Parkinson's Disease
- H.** My Mommy Has PD...But It's Okay!

SUPPLEMENTS

(order by number)

- 4.** Keys to Caregiving
- 5.** Hospitalization of a Parkinson's Patient
- 6.** The Living Will and Durable Power of Attorney for Health Care

- 7.** Parkinson's Disease and Oral Health
- 8.** The Family Unit and Parkinson's
- 10.** The Challenge of Parkinson's Disease: Adapting to a Nursing Home
- 13.** Medical Management of Parkinson's Disease and Medications Approved for Use in the USA
- 16.** When Should Parkinson's Disease Patients Go to the Emergency Room?
- 17.** Neuro-ophthalmology and PD
- 20.** Fatigue in Parkinson's
- 21.** Dr. Andrew Weil's Recommendations for Healthy Aging
- 22.** Depression and Parkinson's
- 23.** Incontinence and Parkinson's
- 24.** Employment and Parkinson's
- 25.** Constipation and Parkinson's

FLYERS

- Basic Information about Parkinson's Disease
- National Young Onset Center
- Medications to Be Avoided or Used with Caution in PD
- 34 Helpful Hints to Improve the Quality of Life of People with Parkinson's
- The Importance of Having a Will

WEB SITES

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

DVD

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

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