

Parkinson's Perspective



This issue is sponsored by Teva Neuroscience.

Letter from the Medical Director

In this newsletter, we revisit deep brain stimulation (DBS) for Parkinson's disease for several reasons. Experience continues to demonstrate that DBS is a remarkably safe and effective therapy. In one study, patients were randomly selected, for example, by a role of the dice, to either have DBS or the best medical therapy. Those who had DBS had greater improvement than those who received best medical therapy. In other studies, patients who completely failed with medications improved with DBS. Also, DBS is more effective, improving symptoms 50%, compared to 29% with gene therapy. Fetal-cell transplant failed to improve Parkinson's disease symptoms, and more than half the patients had complications with involuntary movements, or dyskinesia. As yet, there is no reason to believe that stem cells will fare any better than fetal cells. Further, gene therapy, nerve-growth factors, and potential stem-cell treatments all require surgery and are not likely to be any safer than DBS. Also, these therapies are likely to be years away for the average patient while DBS is available today. Despite these facts, there appears to be greater enthusiasm for other therapies over DBS. We know many patients not being referred for DBS who would benefit from this remarkable therapy.

There likely are many reasons that patients do not receive DBS. Many physicians either are unaware of the therapy or underestimate the potential benefit and overestimate the risk. Other physicians may decide the patient's condition is not bad enough for surgery, which is a mistake. No physician knows how much a patient suffers, and only the patient and his or her family members can decide if the potential benefit outweighs the risks. This should be a decision for the patient and family. The role of the physician is to educate the patient and his or her family, so the patient and family can make the decision.

Certainly, there are risks with DBS surgery. For every 100 patients who have DBS surgery, two or three will

have a serious and permanent complication, such as paralysis, loss of vision or speech, or changes in personality, thinking, or memory. Yet, 97 out of 100 patients will do well. For these reasons, patients first should exhaust all reasonable attempts at medications. But patients who have tried every reasonable combination of medications and continue to have a poor quality of life should consider DBS and consult with physicians experienced in the procedure. When a patient and family members consider the risks of DBS surgery, they also need to consider the risks of not doing the surgery, which include continued severe symptoms of Parkinson's disease and the associated risks and complications, such as falls and serious injury.

DBS improves many of the symptoms of Parkinson's disease for many years. However, for some patients, difficulty with walking continues to be a problem and can worsen following DBS surgery, while the other symptoms are improved. For those patients, DBS of the pedunculopontine nucleus (PPN) can improve walking and balance (see accompanying article). This surgery is done in the same manner as regular DBS.

Some patients who have significant problems with thinking, memory, mood, or personality may not be candidates for DBS. For these patients, epidural motor cortex stimulation (EMCS) is a potential alternative (see accompanying article).

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Electronic Newsletter

If you would like to receive the newsletter in electronic format, please e-mail parkinsons@neurology.wisc.edu. Otherwise, it will continue to be delivered via the U.S. Postal Service.

This newsletter is intended for educational purposes only and should not be interpreted as providing medical recommendations. Patients are advised not to change their treatment without the advice and consent of their treating physician. The editor of the newsletter is solely responsible for its content.

Letter from the Medical Director (continued)

The remarkable effectiveness of DBS also presents significant challenges, because of the lack of awareness by physicians and other healthcare professionals. Many patients who live great distances from Madison have problems finding local physicians and healthcare professionals who can provide postoperative management of their DBS and Parkinson's disease. Also, patients with implanted DBS systems who need emergency medical care may find that local physicians and healthcare professionals are unaware of or unfamiliar with DBS. We encourage physicians and healthcare professionals to contact UW physicians when they encounter our

patients in the emergency room. Emergency room physicians may avoid certain procedures because they are unfamiliar with DBS, or they may expose patients to risky procedures.

Sincerely,



Erwin B. Montgomery, Jr., M.D.
Medical Director, APDA Information and Referral Center
University of Wisconsin–Madison

Alive and Wired—Life after DBS

Each person's Parkinson's story is different. I learned early in my "Parkie" days that the progression of the disease is unique for each of us. Mine began as a dragging right foot and a tremor in my right hand and later became rigidity and slowness on both sides of my body.

PD symptoms vary like Wisconsin weather and worsen with stress, cold temperature, fatigue, and medicines that wear off. Each day was unpredictable. My symptoms were getting worse, and although I expected them to worsen, it was going fast. I got the diagnosis of idiopathic chronic PD at age 46, after spending three years searching for what was wrong. My hope for a better quality of life was through a surgery called deep brain stimulation (DBS).

Deep brain stimulation is not a cure. It is an incredible surgery, which, though difficult, can take away some of the motor symptoms of PD. It is like being given back time that you lose with PD. I was 56 years old when I had DBS surgery. Parkie symptoms were difficult and had cost me, in that I couldn't fully be the wife, mom, teacher, and friend I wanted to be. Caring for my house and myself became difficult. My reflexes were slowed, and I couldn't drive, walk, or communicate well. I felt old before my time.

I was in Stage III of PD. I couldn't let this happen so early in my life. I had been an athletic runner, skier, and storyteller in school and the community. I kept try-

ing different medicines that controlled my symptoms briefly with wearing off and side effects. I felt anxious and unable to relax—I would pace without relief from movement.

Friends and family encouraged me to pursue DBS. My movement disorders doctor thought I should continue to seek relief through medicine. I sought a second opinion at Froedtert hospital, and their team of doctors educated me on DBS. They expected the surgery to be a success as they tested my diagnosis, my psychological and cognitive abilities, and my ability to withstand the surgery itself. I passed all the tests with stubborn Norwegian fortitude. I expected and was given compassionate care. The risk of stroke, infection, or death was small. I was afraid, but the alternative of an illness that was worsening was with me. I had to sign papers that said I understood and that the surgery was risky and could cause my death. My husband was asked if he'd be there for me. He was told by the doctors they would take good care of me.

The DBS team videotaped and observed me on and off meds. When on, I was better. The meds helped but were wearing off each day, leaving me with pain and muscle stiffness. I hoped the surgery would decrease the amount of medicine needed and increase my quality of life. I was hopeful and prepared myself for the surgery with rest and relaxation, prayer, and lots of reading.

I met with the nurses and the DBS team doctors. They had done the surgery numbers of times with great success. They were especially concerned that they locate the substantia nigra (STN) in my central brain with an electrode. They made maps of my brain with MRIs and CAT scans to find it.

I was awake during both surgeries, so that I could ask and answer questions. They established my level of awareness by having me state my name or the date and where I was. It did not hurt as the electrodes went in, because the brain feels no pain. I had local anesthetic when they screwed a metal frame into my skull and drilled a small hole in my skull. I could hear and talk to the doctors throughout the surgery. The nurses, doctors, and anesthesiologists gave my never-ending list of questions brief responses, like “brains come in all sizes” and “yes, we have to shave all your hair each time.” There were cheers in the OR when we heard the snap, crackle, and pop sounds that clearly meant success in finding the right spot for the electrode placement. Placement was important to the relief of symptoms—close was not good enough. The first implant was on the right side of my brain.

I went to neuro ICU for the first 24 hours and could only see my family briefly. The next day, I was walking in the hall with my shaved head and feeling rather well for someone who had just had brain surgery!

When I went home three days later, I noticed my voice was louder, and I was talking at a faster rate and clearer.

A month went by, and I was ready for the second implant. I was awake during surgery and heard cheers as the doctors located precisely the correct spot on the left side of my brain. They moved my extremities to confirm that my range of motion was restored. I was able to talk to them and counted to ten. They ran electricity through the electrode and confirmed that the wires were working. I was on the home stretch. I kept going, and a week later, I had two pacemaker-like devices surgically placed in my chest. Then there was the exciting day when I was turned on with 2.3 volts of electrical charge to each side.

I am now taking two pills a day versus eleven pills before DBS, and I am well. My symptoms are less than

they were. I can drive a car again safely in local traffic. Remaining Parkie symptoms after DBS are different for each person who has the surgery. I still have some facial masking, but the muscles in my face are more relaxed—I smile and laugh more. I still have balance issues and fall easily if I’m not careful. The once rigid muscles relaxed at last. My optimism has returned with regular exercise. The speed at which I move has quickened.

I feel I can do more now, and I try not to say, “I can’t.” The results of DBS surgery vary with each person. To me, it seems best not to wait but to have it earlier, before the atrophy of muscles. It is FDA approved and has helped many people; me for one. Thanks to the caring doctors and nurses and to my family and friends for never giving up on me.

I am a “live-wire” Parkie—and that’s a fact. I enjoy life more since DBS. My heart is light and new. DBS surgery has given me a better quality of life. I am grateful to move with greater range of motion and reflexes. I would consider it an option for those like myself who qualify for the surgery. I am mindful of my illness, but it is no longer a central factor to each day. I am able to live again without so many difficult moments.

by Connie Fausett

Congratulations!

Congratulations to Dr. Catherine Gallagher, a neurologist with the Movement Disorders Program at UW Hospital and Clinics and the Veterans Affairs Administration. Dr. Gallagher received a four-year career development award through the Department of Veterans Affairs. She is exploring the cause of symptoms in Parkinson’s disease with the use of Positron Emission Tomography (PET) and Magnetic Resonance Imaging (MRI).

Deep Brain Stimulation: What, How, Where, and for Whom

Deep brain stimulation (DBS) is a surgical procedure that involves placing a set of electrodes deep in the brain and providing electrical stimulation. Typically, the brain targets are the subthalamic nucleus and globus pallidus internal segment. However, new targets have been identified recently (see accompanying articles on stimulation of the motor cortex and the pedunculo-pontine nucleus). The electrodes in the brain exit the skull through a small hole and connect to an extension that leads to an impulse generator in the chest. The entire system is under the skin.

DBS of the subthalamic nucleus and globus pallidus are approved by the Food and Drug Administration (FDA) for Parkinson's disease. Stimulation of the pedunculo-pontine nucleus and the motor cortex (epidural motor cortex stimulation, or EMCS) use FDA-approved devices. Although not specifically approved by the FDA, these therapies are considered standard and accepted "off-label" treatments.

Surgical therapies for Parkinson's disease have been done for many years, even before the development of levodopa. However, earlier therapies involved purposeful destruction of brain structures, such as the globus pallidus. Even then, neurosurgeons stimulated the globus pallidus prior to destroying it. If the patient's symptoms got better with this test stimulation, the surgeon knew the electrode was in the right place and would destroy the target by heating the tip of the electrode. With the development of new technologies, the electrodes are left in place for continuous stimulation, and there is no need to destroy the globus pallidus. DBS surgeries are much safer and more effective than the old destructive surgeries. Electrodes can be adjusted continuously to tailor the therapy to the patient and modify the treatment as the disease changes.

DBS is remarkably effective for patients with Parkinson's disease and other neurological and psychiatric disorders. DBS is more effective than the best medication therapies and succeeds even when every medication and even brain transplants fail. However, given the 2-3% risk of a serious and permanent complication, such as paralysis or changes in strength, vision, thinking, memory, mood, or personality, patients are encouraged to first optimize their use of medications.

If reasonable attempts at medications fail, patients and family members should consider brain stimulation.

There is a concern that many patients who do not have satisfactory control of their symptoms with medications, and perhaps their physicians, delay considering DBS or EMCS because symptoms are not severe enough. Only the patient and his or her family can know how much the patient suffers and what he or she is willing to risk for the chance of being better.

Some patients or their physicians may be holding out for stem cells, gene therapies, or glial-derived nerve growth factors (GDNF). However, these therapies are many years from accepted use in patients and will entail surgery, making them at least as risky as DBS. Further, preliminary studies suggest that gene therapy, cell transplants, and GDNF are unlikely to be as beneficial as DBS and are not likely to be a cure any more than DBS. For many patients, delaying DBS means continued suffering and the risk of complications of Parkinson's disease.

These observations are not to suggest that every patient should have DBS. Actually, 75-80% of patients may never need DBS surgery and may have satisfactory control with medications alone. But, patients whose quality of life is less than what they want or hope, and their families, should consider DBS and discuss it with neurologists who are expert in DBS.

It is important to know that while the FDA regulates the sale of DBS systems, it does not regulate who can implant these systems. Further, there is no independent accrediting organization that authorizes or endorses any particular surgeon or physician. While device manufacturers provide lists of physicians who provide DBS, these should not be considered as endorsement of or testimony to the physicians' or surgeons' knowledge and skills. The decision about who to see about DBS is entirely up to the patient and his or her family, although it often is influenced by the patient's medical insurance. Even then, it can be worth some out-of-pocket expense to get the best advice.

The DBS surgery team consists of a neurosurgeon, a movement disorders neurologist, a neurophysiologist, and other healthcare professionals. Generally, it is the movement disorders neurologist who decides to

proceed with DBS surgery, because a key question in considering DBS is whether the patient has exhausted all reasonable medication options. It would be a tragedy if a patient who had DBS was one of the two to three patients out of 100 to suffer a severe and permanent complication that could have been avoided by the proper use of medications. Indeed, in our practice, for every patient we refer to the neurosurgeon, three other patients are deferred, because they have not had the full benefit of medications. We often work with local physicians to optimize medications, and if the patient continues to have a poor quality of life after the medications are optimized, we then reconsider DBS surgery.

In addition, it is important to be sure that the patient's form of Parkinsonism is one that will respond to DBS therapy. Only about 75% of patients with Parkinsonism have idiopathic Parkinson's disease. The other forms of Parkinsonism do not respond to DBS, and these patients often worsen following the procedure.

Just as the FDA does not regulate who can do DBS surgery, neither does it regulate how the surgery is done. Consequently, surgery centers may vary in how they perform DBS. For example, while all centers use MRI and CT scans to find the targets in the brain, some do not take the additional and important step of using microelectrode recordings. These recordings, which are done by neurophysiologists, use fine electrodes to record the electrical conversations among individual neurons in the brain in order to identify the exact location to implant the permanent DBS electrode. MRI or CT scans alone are insufficient, and surgeons who do not utilize microelectrode recordings decrease the chances of a good outcome for their patients, in the opinion of most experts.

It is critically important that the patient and family establish who will provide post-operative care and programming of the DBS system before the surgery occurs. Patients and families should be aware that their local physician may not be trained or willing to provide post-operative care, and the patient may have to travel some distance to a DBS center for post-operative care. Also, some centers will not provide post-operative care if the DBS surgery was not performed at that center.

Successful DBS surgery requires specialized knowledge and skill, and skill requires practice. When considering where to go for DBS surgery, patients and family members should seek out those centers that have dedicated programs in DBS and perform enough DBS surgeries to maintain knowledge and skills. A surgeon who performs only a few DBS surgeries a year is less likely to maintain the necessary skills of one who does 15 or more a year.

When considering DBS surgery, patients and family members should:

1. Shop around and compare.
2. Ask whether the center does microelectrode recordings.
3. Ask who is on the DBS surgery team.
4. Ask for the curriculum vitae (CV) of the neurosurgeon, neurologist, and neurophysiologist. The CV is a summary of the person's education and experience. A good neurosurgeon, neurologist, and neurophysiologist should be willing to provide their CV.
5. Ask if the neurologist did a fellowship in movement disorders.
6. Ask if the neurosurgeon do a fellowship in stereotactic and functional neurosurgery.
7. Ask how many DBS surgeries were performed at the center during the previous year.

Pedunculopontine Nucleus: What you need to know

Your movement disorders neurologist may have already mentioned deep brain stimulation (DBS) as an option in surgical management of Parkinson's disease (PD) symptoms. DBS is approved by the Food and Drug Administration (FDA) for implantation into the subthalamic nucleus (STN) and globus pallidus interna (GPi) for the treatment of PD. Symptoms likely to be improved with STN or GPi DBS include slowness of movement (bradykinesia), shaking (tremor), an inability to initiate movements (freezing), and rapid changes in response to medication (motor fluctuations). After STN or GPi DBS, some patients are able to decrease total medication dosages and/or decrease the number of times per day medication must be taken. Decreasing medication doses has been helpful in certain patients who must balance medication side effects with improvement seen on the medications.

Your movement disorders neurologist may have appropriately advised you that gait and balance problems have been particularly difficult to improve in patients with STN or GPi DBS despite other improvements mentioned above. If you are experiencing gait or balance problems, such as an inability to initiate movement despite appropriate medication,

or so-called "freezing of gait in the on state," you will be interested in results of DBS in a new brain location, the pedunculopontine nucleus, or PPN. If you have had surgery for STN or GPi DBS and experienced improvement in upper-extremity function only to lose improvements in gait or balance, PPN DBS may provide another surgical option.

What is the PPN, and is DBS of the PPN right for you? The PPN is a collection of cells, like the STN or GPi, with interconnections in the motor circuit associated with movement and balance. The PPN lies in the brain stem just posterior and inferior to the STN. The surgical methods and devices used are the same as those approved by the FDA for STN and GPi DBS. Certain centers around the world are gaining experience with implanting the PPN alone or in conjunction with STN DBS. Patients with STN and PPN DBS have shown improvement in gait and balance over STN stimulation alone. Surgical risks are similar to DBS of the STN or GPi. Ask your movement disorders neurologist or DBS neurosurgeon if PPN stimulation is indicated in the surgical management of your PD.

FROM THE EDITOR

This is the time of year many people have been waiting for, so they can be out and about, getting sun and exercise. I hear stories of people with Parkinson's getting out of the house and walking up and down the street to keep moving. This is a great spirit to have—not allowing Parkinson's to keep you down.

In my position, I see the different ways people react to Parkinson's disease, and I know about the possibilities out there for help. A diagnosis of Parkinson's is life-altering and can put a person down in the dumps, but it's not the end of the world.

That may sound harsh, but I know many people who do not let Parkinson's run their world. They do

everything they can to live life on their own terms. I have seen a big difference in symptoms and overall quality of life in those who have this attitude compared to those who think the world is out to get them.

Sometimes we don't understand why bad things happen, but when life hands you lemons, it's best to make lemonade. It's true that I don't know what you are going through, but I see people with Parkinson's disease all the time, and I see what a winning attitude can do. Please don't let Parkinson's win. You have a life, so live it.

—Jessica Hahn, Coordinator
APDA Information and Referral Center

UW/VA Madison Brain Bank

The Brain Bank in Madison, Wisconsin, was established in 1995 and received an Institutional Review Board (IRB) approval to collect brain tissue from deceased individuals and neurosurgical patients to aid scientific research. In 2006, state funding allowed the Brain Bank to expand its scope and become registered as the University of Wisconsin/Veterans Administration Madison Brain Bank. The Brain Bank collaborates with the Wisconsin Comprehensive Memory Program, Wisconsin Alzheimer's Institute, and the Alzheimer's Association and is prominently active in the public domain across the state of Wisconsin.

The UW/VA Madison Brain Bank seeks donations from patients who are diagnosed with a neurodegenerative disease, such as Alzheimer's disease or other related dementia, Parkinson's disease, Huntington's disease, motor neuron disease, multiple sclerosis, brain tumors, and other rare or uncommon diseases of the brain. Donations from individuals who are not affected by a neurologic disease are also highly sought after, as the availability of healthy tissue for scientific comparison is essential to successful research. Through continued tissue donations, the UW/VA Madison Brain Bank hopes to actively participate in advancing the knowledge of diseases such as Alzheimer's and Parkinson's.

Many donors gain satisfaction from knowing their donation will contribute to science and potentially help others who are or will be affected by similar neurological or neuromuscular diseases. The donor's family will receive an autopsy report that may confirm the clinical diagnosis and may help to establish an accurate family medical history. Confirmation of clinical diagnosis may allow some families to take preventative measures or allow for participation in other research studies.

Brain donation is typically limited to brain tissue, blood, and cerebrospinal fluid. However, the spinal cord and samples from skeletal muscles and peripheral nerves are also collected from donors who have been diagnosed with diseases such as amyotrophic lateral sclerosis (ALS) or multiple sclerosis.

If you wish to donate, it is important that your family members and physician know your wishes.

Individuals who have been seen by a physician at the University of Wisconsin Hospital and Clinics, the Veterans Hospital in Madison, or individuals who are or have been enrolled in a research study with the Wisconsin Comprehensive Memory Program can donate at no charge. For all others, there is a \$900 fee, which covers the cost of autopsy, brain examination, and issuance of a diagnostic report. Contact your funeral director to find out if there are additional costs for transporting the body to and from the Madison VA Hospital.

For further information, please contact the UW/VA Madison Brain Bank at 608/256-1901, ext. 11767, or brainbank@medicine.wisc.edu. For information about other Brain Banks around the United States, go to <http://www.ninds.nih.gov/funding/research/parkinsonsweb/brainbanks.htm>

Facilitator Needed for New DBS Support Group

We would like to start a Deep Brain Stimulation (DBS) support group but need someone to facilitate it. The APDA Information and Referral Center can help if needed but is unable to facilitate due to other commitments. If you are interested in facilitating this group, please contact Jessica at 608/263-7991.

Epidural Motor Cortex Stimulation (EMCS)

A new method of brain stimulation for patients with Parkinson's disease —epidural motor cortex stimulation, or EMCS—involves the placement of electrical stimulating grids over the surface of the brain beneath the skull. Because the brain is not penetrated, the risks are significantly less than in DBS, such as the risk for increased problems with thinking, memory, mood, or personality. EMCS provides an option for patients who already have these problems and are not candidates for DBS.

Research shows that DBS of the subthalamic nucleus or globus pallidus works by activation of the motor cortex, which lies on the surface of the brain. EMCS is designed to activate the motor cortex directly and is much safer, because the electrodes are placed on the surface of the brain and do not require penetration of the brain.

The surgery utilizes FDA-approved devices that have been used for spinal cord stimulation and DBS. Consequently, EMCS is considered standard accepted medical care and is not experimental or investigational. It should be covered by insurer just as DBS. Post-operative management is similar to DBS.



We recommend that patients who, for whatever reason, are not candidates for DBS surgery consider EMCS. While we do not have a great deal of experience with EMCS because of the relatively few patients who have had this surgery compared to thousands who have had DBS, patients who are not candidates for DBS surgery are urged to consult with physicians experienced with EMCS and DBS.

MEET THE STAFF

Michelle Ciucci, Ph.D., CCC-SLP

We are pleased to introduce Michelle Ciucci, Ph.D., CCC-SLP. Dr. Ciucci is a postdoctoral fellow in the Department of Otolaryngology and an associate lecturer in the Department of Communicative Disorders. She has an NIH grant, "Vocalization Deficits in Parkinsonian Rat: Does levodopa help or harm therapy?"

Dr. Ciucci completed her doctorate at the

University of Arizona in 2006 in Speech, Language, and Hearing Sciences and Neuroscience. She was on the Executive Committee of the Board of Directors of the Arizona Chapter of the APDA. From 2006 to 2007, she was a postdoctoral fellow in the Department of Psychology in Behavioral Neuroscience. Dr. Ciucci's primary areas of interest are in motor control for speech and swallowing, with a focus on Parkinson's disease.

Greetings

HELP WANTED—URGENT: The Wisconsin Chapter APDA board of directors has two critical vacancies: treasurer and at-large member.

Our chapter workforce is small, and it is vital that we fill these important positions.

If you or someone you know is interested in assisting the chapter on a volunteer basis, please contact Jessica at 608/263-7991 or parkinsons@neurology.wisc.edu.

We regret that the demands of family and work resulted in the recent resignations of Karen Bindl and Lindsey Carlstrom. Thank you, Karen and Lindsey, for your outstanding contributions to the chapter. Your hard work and skills were invaluable, and you will be missed.

Wedding Bells

The chapter is pleased to announce that Jessica is getting married in September. We aren't quite sure how to pronounce her fiancé's last name, but ask, and she'll tell you. Congratulations, Jessica and Trevor. We wish you the best.

Walk the Walk

Thank you to everyone who came out for our third annual Parkinson's walk-a-thon on April 6. This event gets bigger and better every year. There were 380 walkers registered, and we raised over \$24,000 for Parkinson's research. Governor Jim Doyle proclaimed April 2008 Parkinson's Disease Awareness Month in Wisconsin. Many thanks are in order:

- Our *corporate sponsors*: A to Z Rentall, *Brava Magazine*, Coca-Cola Bottling Company of Madison, Charter Business, Dale's Service & Refrigeration, High Energy Mobile DJ, Medtronic, Inc., O'Gara Publishing, Research Products Corporation, Teva Neuroscience, Inc., UBC, Inc., and Valeant Pharmaceuticals N.A.
- The generous *raffle donors*: American (Apple i-Pod Nano), Attorney Melinda Gustafson Gervasi (50 percent off value of estate plan), Blain's Farm & Fleet of Watertown (Oster cordless pet grooming kit, Dale Earnhardt grill covers, wall clock, Scrubbing Bubbles automatic shower cleaning kit),

Karen Bindl (Ghirardelli gift basket), Brendan Budack (Pampered Chef gift certificate), Chula Vista Resort (junior suite stay and waterpark passes), Condon Jewelers (gold-tipped rose), Barbara Ann Cowan (Stampin' Up gift basket), Dale's Service & Refrigeration (carbon monoxide detector), Green Bay Packers (signed Packers football), Michael J. Fox Foundation for Parkinson's Research ("Lucky Man" books and Fox Foundation tees), Jazzman (umbrellas), Peacock (gift certificate), Sacred Feather (leather wallet), Trek Bicycle Corporation (Trek bike), and Wisconsin Chapter APDA (Bo Ryan—autographed Badgers basketball).

- Sbarro's Italian Eatery of East Towne, which donated pizza for the volunteers after the walk.
- And, our *volunteers*, without whom the walk wouldn't happen: Karen Bindl, Floyd and Carol Carlstrom, Lindsey Carlstrom, Jason and Kim Crapp, Pam and Gary Crapp, Gwenn and Dave Davies, Lynn and Bill Freimuth, Jessica Hahn, Kathleen Hansen, Angel Hodsdon, Holly Hoffman, Jillian Jonen, Lorraine Jonen, Joyce and Russ Kaping, Jane Leahy, Dale & Nancy Ninmann, Myrna and Cheryl Peterson, Tracy Puralewski, Randy Samborski, Deb Simon, Lisa Statz, and Deb Thomas.

New Support Group in Fox Valley

Changes are coming to the Fox Valley. Beginning in September, the Young-Onset Support Group in the Valley will meet at noon on the third Saturday of the month. Meetings will be held at the Neuro Spine Center of Wisconsin, 5320 West Michaels Drive, Appleton.

The first meeting is Saturday, September 20, 2008, with a light lunch served at noon, followed by the meeting at 1 p.m.

Everyone is welcome—caregivers, family, and, yes, those with Parkinson's—to learn about new medicines, exercises, medical procedures, and more. The most important part of this group will be learning and sharing. You are not alone—come to the support group and meet others with young onset Parkinson's disease.

Please call Vera Ramacitti at 715/258-9829 to RSVP for the lunch at the September meeting.

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A Parkinson's Symbol



Karen Painter, from Washington State, has young-onset Parkinson's. She has designed a stylized tulip pin that she hopes will do for Parkinson's awareness what the pink ribbon has done for breast cancer. The design is based on the Dr. James Parkinson tulip, which has been associated with Parkinson's awareness since it was developed in 1980 by a Dutch horticulturalist who had PD.

Jean Burns, of Arizona, collaborated with Karen, and the design has been copyrighted and is being distributed nationally as a symbol of individuals who have Parkinson's disease, rather than being symbolic of a specific organization.

While it does not replace the official corporate APDA logo, which is our legal and copyrighted identification, the chapter is pleased to be part of a grassroots effort to establish a national symbol for Parkinson's awareness. Pins were available at our annual walk in April and have proven to be very popular. Check out the website, www.pdplan4life.com, for more information.

Caregiver Support

Caregiving can be hard work, physically and emotionally, and sometimes we need a break. This isn't anything to be ashamed of. United Way has estimated that there are 42,000 family and unpaid caregivers in Dane County, and caregivers often experience poor health, depression, anxiety, and higher mortality than the general population.

If we're going to do a good job, caregivers of people with Parkinson's should take advantage of any help available, and there are two good resources in Dane County.

Residents of Dane County who provide care to an adult 60-plus years of age or any age for those with dementia are eligible for services from the Area Agency on Aging of Dane County. The care recipient must have significant cognitive or mental deficits or need assistance with at least two activities of daily living, such as eating, bathing, toileting, dressing, etc. There is no income or asset test required to qualify for caregiver assistance.

Supplemental services and respite care are available on a limited basis to complement care provided by caregivers. Services are not intended to augment or

supplant other long-term care programs (Community Options Program, Alzheimer's Family Caregiver Support Program, Care Wisconsin Partnership, etc.).

Examples of "caring for the caregiver" services include respite (in home or day center); personal care training by a registered nurse or medical professional on personal care techniques; transportation to and from support groups and other activities that contribute to the caregiver's ability to continue giving care; home chores; and home modification and equipment that can assist a caregiver in meeting the needs of a family member.

The National Family Caregiver Support Program is federally funded and available nationwide. To access caregiver services within Wisconsin, call toll-free: 866-843-9810, or visit www.wisconsinicaregiver.org. Nationwide, call Elder Care Locator at 1-800-677-1116 or visit www.eldercare.gov

Independent Living, Inc., is a non-profit, multi-service agency that assists people with disabilities and older adults, enabling them to live with dignity and independence while maintaining health and well-being. Clients and families may receive up to 31 hours of care from an in-home personal attendant or a five-day stay at Independent Living's Segoe Gardens Assisted Living facility, which offers 24-hour care. Participants must meet income eligibility guidelines for this program.

Resources:

*Claire Culbertson, Caregiver Coordinator
Area Agency on Aging of Dane County
(608) 261-5679 or culbertson@co.dane.wi.us*

*Intake Coordinator
Independent Living, Inc.
(608) 274-7900 or intake@independenliving.com*

Stem Cell Update

The U.S. Patent Office recently dismissed all stem cell claims from California and New York, which means the Wisconsin Alumni Research Foundation (WARF) can collect profits from the commercialization of any products related to embryonic stem cells. The patents were re-examined following challenges by New York's Public Patent Foundation and California's Foundation for Taxpayer and Consumer Rights. (*In Business Magazine*, April 2008)

UPCOMING EVENTS

Chapter Meetings

Second Wednesday of the month, 5:30 p.m.
UWHC Neurology Library (H6/581 CSC)

Shaking Up Parkinson's Disease Luncheon

September 14, 2008
Grand River Center, Dubuque, IA
RSVP by September 8, 2008
Contact: Jessica Hahn (parkinsons@neurology.wisc.edu
or 608/263-7991)

Young-Onset Support Group in the Valley

Beginning September 20, 2008, and the third Saturday
of the month thereafter, noon
Neuro Spine Center of Wisconsin, Appleton
Contact: Vera Ramacitti, 715/258-9829

World Stem Cell Summit

September 22–23, 2008
Alliant Energy Center, Madison
www.worldcellstemsummit.com

Parkinson's Disease Walk-a-Thon

October 4, 2008
City Center Plaza, Downtown Appleton
Contact: Amy Helein, 920/213-0810 or
ahelein@hotmail.com.

Parkinson's Disease Symposium

October 19, 2008
Sheraton Hotel, 706 John Nolen Drive, Madison
Speaker: Marina Emborg, M.D., Ph.D.
Contact: Jessica at 608/263-7991 for information

Wisconsin Chapter—American Parkinson Disease Association

P.O. Box 7513 • Madison, WI 53707-751 • 608/263-7991
chapter@wischapterapda.org • www.wischapterapda.org
National Website: www.apdaparkinson.org

Name _____

Address _____

City _____ State _____ Zip _____

Phone: Home () _____ Work () _____

Phone: Cell () _____ E-Mail _____

Preferred Method of Correspondence: Email _____ Postal _____

Patient _____ Caregiver _____ Other _____

Put me on mailing/membership list: Yes _____ No _____

I would like to be involved with:

Support Groups _____ Fundraising _____ Walk-A-Thon _____ Board _____

Membership Drive _____ Other _____

Membership is renewed annually in September. The optional \$5 membership
fee helps the chapter "ease the burden...find the cure."

\$5 _____ or Other \$ _____ (optional)

Please send application and donations to the above address or call 608/263-7991.

Signature _____ Date _____

ALL DONATIONS ARE TAX DEDUCTIBLE

BECOME A MEMBER TODAY!

The Wisconsin Chapter APDA is a not-for-profit, volunteer organization committed to raising public awareness of Parkinson's disease and dedicated to easing the burden on Parkinson's patients, families, and caregivers.

PUBLICATIONS

Use this order form or call 608/263-7991.

_____ **Basic Information about Parkinson's Disease**
(4-page brochure)

_____ **Parkinson's Disease Handbook**
(symptoms, causes, treatment; 40-page booklet)

_____ **Be Active** (25-page exercise program for people
with Parkinson's disease)

_____ **Be Independent** (32-page booklet on equipment
and suggestions for daily living activities)

_____ **Speaking Effectively** (34-page booklet on
speech
and swallowing problems with Parkinson's)

_____ **Good Nutrition in Parkinson's Disease**
(26-page booklet)

_____ **Young Parkinson's Handbook** (78-page booklet)

_____ **Aquatic Exercise for Parkinson's Disease**
(20-page booklet for patients and families)

_____ **My Mommy Has PD . . . But It's Okay!**
(20-page booklet for young children)

HALL OF MEMORY & HONOR

The following individuals have been recognized through donations to the Wisconsin Chapter APDA.

In Honor of...

Donald Ballweg
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Al Broz
Dale Carlstrom
Eunice Chagnon
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of the Alliant Energy
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Here to Serve You!

The American Parkinson Disease Association Information and Referral Center is here to serve you. We have a wealth of information: books from APDA that are available free of charge, a list of Wisconsin support groups, a list of neurologists who specialize in Parkinson's disease, and any information you are looking for about Parkinson's disease. Our mission is "to ease the burden, to find the cure," and that is what we want to do: ease as much of the burden as we can for you. Please contact Jessica Hahn at 608/263-7991 or parkinsons@neurology.wisc.edu for more information.

Parkinson's Perspective is published three times a year for Parkinson's patients, their families, and caregivers. It is produced by the APDA Information and Referral Center and the Wisconsin Chapter of the APDA. This issue is sponsored by UCB Pharma. If you no longer wish to receive this newsletter, please call 608/263-7991 or e-mail parkinsons@neurology.wisc.edu.

—Jessica Hahn, editor



A Parkinson's Publication

APDA Information and Referral Office
600 Highland Avenue
Madison, Wisconsin 53792

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Stamp
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