

Parkinson Pathfinder

THE NEWSLETTER OF THE AMERICAN PARKINSON DISEASE ASSOCIATION
INFORMATION AND REFERRAL CENTER OF WASHINGTON

Spring 2004

Parkinson's Treatment News

The U.S. Food and Drug Administration (FDA) has approved the Kinetra (Medtronic, Inc) dual channel neurostimulator and the Access Therapy Controller for deep brain stimulation (DBS) in Parkinson disease. DBS has been used for over a decade to treat tremor. Two years ago, the FDA approved the use of bilateral (on both sides of the brain) DBS of either the subthalamic nucleus (STN) or the globus pallidus internus (GPi) for treatment of Parkinson disease.

Until now bilateral DBS required two separate stimulators (Solettra, also made by Medtronic, Inc) surgically placed under the skin, one on each side, usually in the upper chest wall. Each Solettra stimulator was connected to a DBS lead on one side of the brain. Now a single Kinetra dual channel stimulator can connect to both DBS leads to provide bilateral stimulation of deep brain targets. A single neurostimulator for bilateral DBS therapy requires fewer incisions. A disadvantage with Kinetra would be that one cannot turn off the stimulator on one side and leave the other side on. There are rare cases where this may be necessary due to stimulation-induced side effects on one side only.

The Access Therapy Controller is a hand held device that has the ability to provide patients with enhanced control over their stimulation parameters. The patients are able to increase or decrease the stimulation voltages by pressing buttons on the hand held device, but within set limits. This allows patients

to alter the stimulation intensity (depending on their medication status) within limited parameters that have been previously set in the physician's office. Usually the range with which the patient can alter the stimulation parameters remains quite limited for fear of stimulation-induced side effects. It is also believed that the battery life for the Kinetra dual channel stimulator is longer than that for the older Solettra, thanks to a more gradual decrease in battery capacity. This could potentially result in less frequent replacement of the pulse generator in the chest wall.

Some centers implant both DBS electrodes on the same day, while others (such as Univeristy Washington and Harborview Medical Center) place the first DBS electrode to treat the more affected side and wait approximately three months before placing the electrode on the other side. The surgical centers that perform bilateral electrode placements on the same day may be more likely to switch to the Kinetra dual channel stimulator. At this time, the surgical team led by Dr. Robert Goodkin at the Univeristy of Washington and Harborview Medical Center is closely studying the advantages and disadvantages of the Kinetra dual channel stimulator.

Contributed by Ali Samii, M.D., Movement Disorder Specialist at University of Washinton Medical Center and at Puget Sound Veterans Health Care.

Keep Moving! with Laurel Campbell Beck, PT

Exercise improves endurance, balance and quality of life; as measured in numerous studies. But where does one start? There are many options. Certainly, gyms and community centers may have equipment and classes that work well for many. There are many places today to practice yoga, tai chi, Feldenkrais, and any number of activities that can contribute to overall health and function. Senior Centers offer classes for people with a range of abilities. For those that like to work more independently, a wide selection of videos are available. Some people enjoy regular exercise through television programs such as "Sit and Be Fit". For those that would like

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Information & Referral Center
UW Dept. of Neurology
 Box 356465
 Seattle, WA 98195
 Phone: (206) 543-5369
 1-888-400-2732
 apda@u.washington.edu

For information packets, literature, or other Parkinson related issues, please contact the Information and Referral Center at the above address or visit our website at

www.waparkinsons.org.

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If you have any comments or suggestions regarding this Newsletter, please contact the I & R Center at (206) 543-5369.

The material in this Newsletter is solely for the information of the reader and should not be used for treatment purposes, but rather for discussion with the patient's own physician. It does not necessarily reflect the opinion of the Seattle APDA I&R Center or that of the Washington State Board.

News from your Washington State APDA

April is World Parkinson's Awareness Month ~ Here are some great ways to acknowledge it



***THE GARDEN CONSERVANCY'S OPEN DAYS PROGRAM** is being held on Bainbridge Island. As part of this national program, Agate Nursery Garden at 16675 Mariner Avenue Northeast on Bainbridge Island will open to the public on April 24 from 10 am –4 pm to benefit the Washington Chapter of the American Parkinson Disease Association and the Open Days Program of The Garden Conservancy. The 6.5-acre Agate Nursery Garden begins with four acres that have been deeded to the Bainbridge Island Land Trust. Descending through a century-old forest, one comes upon a pond inhabited by a red slider turtle, eagles, blue heron, ducks, raccoons, and river otters. There one enters into 2.5 acres reserved as a private residence beginning with a wall garden, swimming pool, and labyrinth, ending on a west-facing beach along Agate Passage. Don't miss the sauna with the sod roof. Anne Holt has a fine collection of Japanese maples, rhododendrons, a large eucalyptus tree, and a unique collection of perennials and woody shrubs.

Nine other outstanding private gardens on Bainbridge Island will also open on April 24th and July 17th. Other Washington Open Days are: Seattle - May 8, June 13 & 20th, Snohomish - July 31st, and Bellevue - August 22nd. Call 1-888-842-2442 for more information.

The Garden Conservancy is the only national not-for-profit organization dedicated to the preservation of American gardens. By inviting the public to visit private gardens through its Open Days Program, the Conservancy strives to strengthen the public's commitment to garden preservation and encourage the appreciation of gardens as living works of art. You can visit them online at www.gardenconservancy.org.



* Join the **1st Annual Parkinson's Ride to the Skagit Valley Tulip Festival**. A group of local PD advocates is organizing the *Tulips Speak for Parkinson's* Bus Trip on Friday, April 9th. This all day event will provide a ride to the Tulip Festival, lunch at the Kiwanis Salmon Bake, plus entrance to Tulip Town and the Roozegarde- all popular features of the festival. The trip will originate in Kirkland and will be accessible for people using wheelchairs. As an added feature, a group of PD advocates on Harley Davidson motorcycles will be accompanying the bus tour for their own *Rollin' Thru the Tulips for Parkinson's* event. To learn more and join in the fun, contact the organizers at (425)396-4469. Call today- space is limited !



* We'll be **Rockin' for a Reason** with Daryl and the Diptones on Saturday, April 17th at the Wintergarden at Bellevue Place in Bellevue. See the enclosed flyer for details of this evening of fun, dancing, 50's décor, prizes and a silent auction and prizes, all to benefit the programs of APDA of Washington. For tickets, call 206-543-5369 (or 1-888-400-2732 toll free)



Ask the Doctor ~ Phil Swanson, MD



Q: *What can I do to help my husband who has PD, who wakes up several times each night and doses off frequently during the day?*

A: It seems that your husband is suffering from a sleep disorder that may well be related to his PD. Studies have reported that up to 3 out of 4 patients with PD can have sleep disturbances, though these are not always severe. There are many causes of sleep disruption. These include: 1) “periodic limb movements of sleep”, causing the legs to involuntarily flex; 2) restless legs, with an uncontrollable urge to get up and move around; 3) discomfort due to difficulties such as trouble turning in bed, leg cramps, worsening tremor, probably due to wearing off of the effect of medications; 4) insomnia due to depression; 5) vivid dreams or hallucinations; 6) excessive sleep during the day; 7) REM sleep behavior disorder, where during dreaming the person moves about and may fall out of bed or kick the spouse. Of course there may be other reasons for interrupted sleep such as needing to urinate because of prostate problems, difficulty breathing due to heart or lung disease, esophageal reflux disease or sleep apnea.

Trying to figure out what it is that keeps your husband

from sleeping is a task for you, him, and your physician to try to solve. If it is mainly trouble turning, cramps in the legs or feet, adding a dose of levodopa at night or during the night may help. Restless legs is often helped by one of the dopamine agonist drugs such as Mirapex. An antidepressant may be helpful if the main problem is early morning awakening. Vivid dreams may be due to too much medication and helped by lowering the dose of PD medications, and in some cases may require a medicine such as Seroquel. REM sleep behavior disorder may respond to a medicine such as clonazepam. Certain sleep hygiene measures can be helpful such as limiting daytime napping.

If you, your husband and your doctor have difficulty coming up with a helpful plan, consider a referral to a “sleep specialist” physician who will have special expertise in analyzing sleep problems.

Dr. Swanson is a neurologist at the University of Washington Medical Center

What you can do about: Getting information

When you are newly diagnosed, or as situations arise along the way, it is good to know a number of places to turn for information and assistance. Below are just a few of the organizations, helplines and websites that people have found to be helpful PD resources.

Local and National Parkinson’s Disease Advocacy Organizations

- American Parkinson Disease Association 1-800-223-2732 www.apdaparkinson.org
- APDA Washington Chapter 206-543-5369 / 1-888-400-2732 www.waparkinsons.org
- APDA Young Parkinson’s Center 1-800-223-9776 members.aol.com/apdaypd
- Michael J. Fox Foundation 1-800-708-7644 www.michaeljfox.org
- National Parkinson Foundation, Inc 1-800-457-6676 www.parkinson.org
- Northwest Parkinson’s Foundation 1-877-980-7500 www.nwpcf.org
- Parkinson’s Action Network 1-800-850-4726 www.parkinsonsaction.org
- Parkinson’s Care Center of Oregon 1-503- 494-7231 www.ohsu.edu/pco/
- Parkinson’s Disease Foundation 1-800-457-6676 www.pdf.org
- Parkinson’s Regional Center of Spokane 509-473-6740
- Parkinson’s Resources of Oregon 1-800-426-6806 www.parkinsonsresources.org
- Parkinson’s Society of Canada 1-800-565-3000 www.parkinson.ca

Additional Online Parkinson’s Information and Support Resources

- Brain Talk Communities: Neurology Support Groups www.brainstalk.org
- Cognition <http://cognition.org>
- National Institutes of Health Parkinson’s Research www.ninds.nih.gov/parkinsonsweb

Information and Support for Seniors and Caregivers

- Family Caregiver Alliance 1-800-445-8106 www.caregiver.org
- Senior Information and Assistance
 - King County 206-448-3110
 - Snohomish County 425-513-1900



PD Tips from Real Experts

More gadgets for making life easier from Mitchell Levy (a.k.a. Gadget Junkie) ~ This month I'm focusing on the bathroom, specifically the shower and/or bath.

PD Tip #1: Washing those hard to reach spots

One of my favorite TV shows is "Queer Eyes for Straight Guys" on the Bravo channel on Tuesday evenings. The show features a "straight" guy who gets a "make over". In one episode, for grooming, they recommend a back brush for the shower and bath... "the back is part of the body too you know"! As a "Parkie", it's not just the back I can't reach! So if you want to get to those hard to reach spots, get a good quality back brush for the shower or bath. Not only does it clean and feel good on the back, but helps with washing legs and other hard to reach spots. The brushes do have a broad range in price. I got my brush at Bed Bath and Beyond for \$4.99.

PD Tip #2: More washing those hard to reach spots

If you don't have a hand held shower head, you really don't know what you're missing. Hand held shower heads are particularly convenient if you have to sit on a chair or stool in the shower. The flexibility of the hand held shower head is wonderful and can be used by hand or stationary as a normal

shower head. The icing on the cake here is that most of the mid-priced models come with several different sprays types for a most enjoyable shower. Prices for handheld shower heads range from about \$19 to \$100. My own personal experience is you can get a wonderful hand held shower head for about \$39.

PD Tip #3 More than you want to know about those hard to reach spots

Obviously between the use of the back brush, and waving that hand held shower head around, there is going to be quite a bit of activity in the shower. And with all this activity, the shower can be a dangerous place. Therefore, I urge you to put Wall Grab Bars in your shower! Wall Grab Bars are not expensive and relatively easy to install. My personal opinion is that you install at least two. For placement and angle, I recommend that you discuss location with your Physical and/or Occupational Therapist.

Do you have a tip to share? Please send them in!

Mitch Levy, a retired engineer, co-facilitates the Young Onset Parkinson's Eastside Network in Kirkland, WA.

Walking with Parkinson's Disease by Ann Zylstra PT

Parkinson's disease (PD) is a disorder which changes the way a person moves. People with PD may develop tremor, stiffness (rigidity), and slowness (bradykinesia) of movement early on in the disease. Balance may be affected as well. Usually these symptoms present asymmetrically; that is, they are initially more severe on one side than the other. All of these symptoms of PD may significantly affect a person's ability to walk.

How does walking change with Parkinson's? This is as variable as the disease. Typical early changes include stiffness on one side causing diminished arm swing, or shortened stride with the affected leg. This change is mild, doesn't affect function, and usually isn't treated. Often just making a person aware of the change can postpone problems related to that change.

Later in the progression of the disease, changes in walking become more apparent. Tripping or 'loss of balance' becomes too frequent to ignore. This is typically seen in the person who has more rigidity or postural instability. Now the emphasis of therapy will be on regaining normal posture; unfortunately, normal posture is very difficult to regain. The brain acclimates quickly to the forward flexed position. One of our earliest reflexes is to keep our head "upright" or horizontally positioned for vision. When the body flexes forward the gaze is no longer "horizontal". To regain this horizontal gaze the chin comes forward and the muscles at the base of the skull tighten. The knees and hips flex slightly leading to tightness in the muscles in back of the thigh. This leads to a slight 'squat' position while walking (and increased difficulty getting out of a low chair or car seat). This posture will lead to a shorter stride with less rolling from heel to toe. The result is that walking

becomes more difficult.

Later still, we see festination and freezing. These changes typically occur when rigidity and bradykinesia are significant. Festination means that the feet essentially can't keep up with the body and speed forward with small "sticky" steps. The feet may stop altogether, called "freezing." At this point treatment is difficult. Often a therapist may try sensory cues to help unlock the freeze or walking aids to allow the legs to catch up with the body. These cues may be visual, auditory, cognitive or tactile. Typically, the cues help free up the person but don't stop the occurrences.

The changes in walking vary from person to person. Often someone with Parkinson's does not receive PT until he or she is very unstable or even falling. At this point treatment is based on trying to regain stability while preserving mobility. Personally, I feel prevention is much easier and far more successful. Anyone newly diagnosed with Parkinson's should encourage a referral to PT for preventative gait training.

Walking is our way of getting from one point to the next. Remember that the act of walking is very complex, and that changes in walking due to Parkinson's disease can potentially be devastating. The progression of Parkinson's currently cannot be stopped or avoided, but the good news is that more is known about the disease every day. Until a cure is found, keep active and don't hesitate to try to prevent any loss of mobility you can.

• Special thanks to Dr. Alida Griffith MD for her assistance with editing this article

Ann Zylstra is a board member of the WA Chapter of the APDA and the lead physical therapist at the Booth Gardner Parkinson's Care Center in Kirkland, WA.

“Challenges in Caregiving: Giving Care, Taking Care”

On Monday June 7th, from 9 am to 4:30 pm at the Tukwila Community Center in Tukwila, Washington, people who provide support to others with disabilities or chronic illness will have an opportunity to participate in a conference designed just for them. The purpose of this annual conference, one of the largest of its kind in Washington, is to provide current, practical information and skills that caregivers can use in their daily caregiver responsibilities. Presenters will discuss such topics as legal and financial planning; coping with stress, grief and anger; management of challenging behaviors; and making the most of doctor's visits. The conference is planned jointly by several private and public aging and disability organizations throughout the Puget Sound region and will also include a large number of exhibits of service providers and agencies. The target audience for the conference includes:

- Family caregivers of adults with chronic illness and disabilities
- Adult children concerned about aging parents
- Aging parents caring for adult children with disabilities
- In-home caregivers: chore workers, COPES workers, individual providers, and home care staff
- Adult family home sponsors
- Adult day care and assisted living facilities staff
- Geriatric mental health service providers

Space is limited. You must pre-register as no “walk-in” registration will be possible.

To receive a conference brochure and registration materials, call the Aging and Disability Services Administration at 360-725-2544 or 1-800-422-3263.

Changes in APDA's Caregiver Support Program

Carin Mack, MSW, who facilitates Caregiver Support Groups in the University District of Seattle and on Mercer Island, announces changes in those groups' schedules as well as additional assistance for caregivers and families.

Group changes Beginning in April, when the Mercer View Community Center closes for reconstruction, the Eastside Caregivers Group will join the University Group at the University Congregational Church for monthly meetings on the Second Tuesday of the month at 2 pm. (Call Carin at 206-230-0166 for further details). Note that this is a change of schedule for the University Caregiver Group also.

Additional Caregiver assistance Carin Mack, a Certified Social Worker with many years of experience working in the field of aging and chronic illness, will be available for short term consultation on matters related to caregiving and family issues for families dealing with Parkinson's Disease. Please call her at 206-230-0166 for more information.

continued from page 1. . **Keep Moving**

specific ideas for starting out, we have listed below some of the many options available in the greater Seattle area. For other areas, check with your local Parks and Recreation Department, Senior Center or YMCA.

Parkinson's Exercise Class: Instructor Debbie Hanson, PT. Community Center at Mercer View 8236 SE 24th Street, Room A-6 (206) 236-3545 T/Th 10:45-11:45

Tai Chi :many options in community, including:

* Swedish Medical Center, 1120 Cherry Bldg (206) 386-2035 T/Th 3:45-4:45 and 5:00-6:00 pm

* Kirkland Senior Center, 425-828-1223, \$35 for 4 wks for residents Th 10:15-11:15

* Redmond Senior Center, 425-556-2314 \$30 for 4 wks Weds 2:30-3:30

Pool Activities are offered at many of the community pools:

*Meadowbrook Pool 684-7522

*Green Lake Senior Water Aerobics 684-0780

*Highline Community Hospital 244-9970

For all Seattle Parks and Recreation facilities, call 684-4075 or <http://www.ci.seattle.wa.us/parks/Aquatics/index.htm>

Hydro therapy classes offered by the Multiple Sclerosis Association of King County are open to people with PD. The classes are located at:

- Odle Pool in Bellevue
- Evergreen Pool in Burien
- Kent Pool in Kent
- Fircrest in Shoreline

Contact Laurie at 206-633-2606 for registration and schedules.

The Lifetime Fitness Program, sponsored by the Senior Wellness Project, offers a low-cost exercise program designed to be safe and effective for seniors with a wide range of physical abilities. These classes meet 3 times a week for a five-week session at many senior centers. Call (206) 727-6295 for details and locations.

Senior Information and Assistance 1-800-448-5025 also has information about classes.

Laurel Beck, MS, PT, NCS, is a Physical Therapy Clinical Specialist at Virginia Mason Medical Center in Seattle

Thank you for your Greatly Appreciated Donations!

Contributions received December 18, 2003 ~ February 5, 2004

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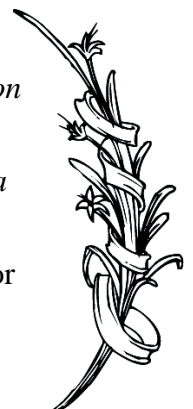
APDA Appreciation

The following corporations are deserving of our sincere thanks for their efforts on behalf of APDA and the Parkinson's community. Please support them in return.

IKEA stores and Boehringer-Ingelheim for underwriting the costs of *Rockin' For a Reason with Daryl and the Diptones*.

Great Clips for their "Great Needs, Great Deeds" Campaign which raised funds for APDA through their fall Clip-a-Thon.

Safeway Food and Drugs for including APDA as a 2003 "Charity of Choice".



Short Takes and Upcoming Events For The PD Community

The Multiple Sclerosis Association of King County will be holding a seminar on cognitive impairments and related assessments, treatments and therapies available on Wednesday, March 24, 6:15-8:15 at the Virginia Mason Medical Center in Seattle. Compensatory strategies for these challenges will also be discussed. The speakers will be Rochell Winnett, PhD, ABPP, Rehabilitation and Clinical Neuropsychologist and Roberta Kelley, MS/CCC, Speech and Language pathologist of the VMMC Physical Medicine and Rehabilitation Department. While this will focus on MS, much should be applicable to PD. Free – donations welcome. Registration is required by contacting MSA at 206-633-2606 or msa@ccom.net.

Booth Gardner Parkinson's Care Center continues its quarterly education series on Parkinson's Disease on Thursday June 24th, 3:30-6pm at the Evergreen Hospital and Medical Center in Kirkland, WA. The topic and presenter are to be announced. To register and for details, call 425-899-3000.

WANTED: Volunteers interested in helping plan this year's PD Research Fundraiser! Each year Washington APDA joins its counterparts all over the country in raising funds to promote continuing research to find the cure for Parkinson's. We are seeking new ideas and people to help us plan this annual Fall event which has traditionally been our Walkathon. Help us choose this year's event!

Call Anne at APDA at 206-543-5369. *Thank You*

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*Please take a minute to do so ~
 we will all Benefit!*



*April is Parkinson's Disease Awareness Month
 Time to Rock 'n Roll or Take a Trip to the Tulips!*