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A B O U T U S

The **Parkinson's Post** is published by the Northwest Parkinson's Foundation, a 501(c)(3) charitable organization.

Our mission is to establish optimal quality of life for the Northwest Parkinson's community through awareness, education, advocacy and care.

We welcome your comments on this newsletter and all our activities.



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Sierra Farris, MPAS, PA-C, programs a patient's deep brain stimulation device. Farris is a DBS programming expert at the Booth Gardner Parkinson's Care Center at Evergreen Hospital Medical Center in Kirkland, WA.

Photo courtesy of Cleveland Clinic

Center expands to meet needs of Parkinson's community

Parkinson's disease touches the lives of so many—patients themselves, of course, but also their family, friends, co-workers and neighbors. Think about the estimated 70,000 people with Parkinson's in the Northwest alone. Now think about the far broader impact of the disease in light of each patient's human support system.

High-quality comprehensive care—the kind that aims to help people with Parkinson's disease stay active over a lifetime—benefits not only the patient but everyone in the life of that patient. When an individual with Parkinson's is able to continue a career, actively participate in his or her community, and engage fully with loved ones, we *all* benefit.

With the help of the Northwest Parkinson's Foundation in partnership with Evergreen Healthcare, the Booth Gardner Parkinson's Care Center opened

its doors in 2000 with a vision of a new model of care—a comprehensive, team approach to Parkinson's that views each patient individually and aims to maximize that person's quality of life.

In this special edition of the *Parkinson's Post*, we highlight the Booth Gardner Parkinson's Care Center, introduce you to the Center's staff, and paint a picture of a very promising future in Parkinson's care.

The Center: 2000-2008

In the seven years since it opened, the Booth Gardner Parkinson's Care Center has touched the lives of thousands of patients. The Center's growing patient base is the result of the tremendous skill, dedication and compassion of its staff. But it's also the outcome of a community

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of patients and caregivers eager for a holistic approach to wellness.

Under the guidance of Dr. Monique Giroux, medical director of the Booth Gardner Parkinson's Care Center, the Center is experiencing significant growth in the number of patients seen and services provided. One aspect of growth has been the launch of a wellness program that includes communication and exercise groups for Parkinson's patients.

In the communication group, facilitated by Center speech pathologist Shirley Glazer, Parkinson's patients practice their speaking volume and clarity with other patients in a relaxed environment. The neurological exercise group focuses on gentle stretch and strength exercises for people with Parkinson's, multiple sclerosis, stroke and other neurological disorders.

Looking ahead

In late 2006, the Booth Gardner Parkinson's Care Center moved from its original site on NE 128th Street in Kirkland, on the Evergreen Healthcare campus adjacent to Evergreen Hospital Medical Center, to a temporary home a short distance away, on the second floor of 13030 121st Way NE, also on the Evergreen campus. (See map on facing page.)

Construction began in 2007 on Evergreen's brand new neurosciences building, depicted in the architectural drawing above. This state-of-the-art facility, which will house the Booth Gardner Parkinson's Care Center beginning in 2009, will mean that comprehensive care for Parkinson's remains under one roof into the future.

The new Center space will be patient friendly and meet the characteristics of a "healing environment,"



meaning it will feature design elements studies have shown can have a powerful therapeutic effect on patients.

Giroux expressed enthusiasm about the new building, the growth in the Center's care services, its expanding research program, and its new wellness-focused classes.

"This is such an exciting time for the Center," she said. "To me, the changes reflect a deepening commitment to the same vision we began with in 2000. It's always been about taking an empathic and creative approach to helping people live better with Parkinson's."

'The changes reflect a deepening commitment to the same vision we began with in 2000 ... taking an empathic and creative approach to helping people live better.'

The comprehensive approach

What do we mean when we talk about "comprehensive" care? At the Booth Gardner Parkinson's Care Center, comprehensive care refers to a holistic, team-based model of care with a goal of treating the person, not the disease. The comprehensive approach means that patients benefit from a range of

specialists in Parkinson's disease, each with a particular focus of expertise but

working in tandem.

The Center's team includes physicians, physician assistants, neuropsychologists, physical therapists, occupational therapists, a speech-and-swallowing specialist, nurses and nutritionists—all specialists in Parkinson's disease.

At the Center, each team member is encouraged to meet the challenge of providing a level of Parkinson's care above and beyond what is available elsewhere. The specialists interact with one another daily to optimize the care and well being of their patients.

Patients benefit from this approach at all stages of the disease. For instance, newly diagnosed and young patients often express concern about their future, work, family and continued independence. Early treatment, then, may focus on the prevention of disability and on emotional, physical and nutritional health.

Many people with Parkinson's benefit from programs that help them develop a sense of empowerment and control over their disease.

Programs to help patients and caregivers manage this complex disease will continue to be added over time as the Center grows.

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On the research front

The Booth Gardner Parkinson's Care Center has been involved for several years in clinical research, including drug trials. The Center plans to continue with studies to evaluate the newest medications and therapies for Parkinson's.

Such studies rely on the participation of willing patients, and more studies mean more opportunities for patients who are eager to help. A clinical trials research coordinator is there to

answer patients' questions about the latest research trials and match patients interested in being involved in research with appropriate studies.

In addition to drug trials, research at the Center will focus on issues related to quality of life, the role of comprehensive care in patient improvement, and the development of care models for chronic disease.

Research into the management of chronic disease is important because illnesses like Parkinson's require a

specific kind of care over a lifetime. A population that is living longer but suffering from more chronic illness makes this area of research particularly salient. With this research focus, the Center strives to be a national leader in the care of chronic disease.

Community partnerships

The Booth Gardner Parkinson's Care Center continues to work closely with the Northwest Parkinson's Foundation and other groups to improve education and awareness.

Center staff were key participants in last November's HOPE Conference on Parkinson's, a collaboration of the Northwest Parkinson's Foundation and the Washington chapter of the American Parkinson Disease Association. Staff presented to the more than 650 patients, caregivers, advocates, clinicians and researchers who attended the conference.

The Center, designated a National Parkinson Foundation Care Center of Excellence in 2006, also continues to work closely with organizations at the national level.

To learn more

To make an appointment at the Booth Gardner Parkinson's Care Center or to learn more about its clinical research trials or wellness programs, call the Center directly at 425.899.3123.

If you live too far from the Center for regular visits, you may benefit from the Comprehensive Care Clinic Program or the Deep Brain Stimulation Comprehensive Program. See Page 7 for more information.

For more information about comprehensive care as practiced at the Booth Gardner Parkinson's Care

Center, see the Parkinson's Disease Foundation's July 2007 article about comprehensive care at www.pdf.org/Publications/newsletters/summer07/team_approach.cfm.

What about wellness?

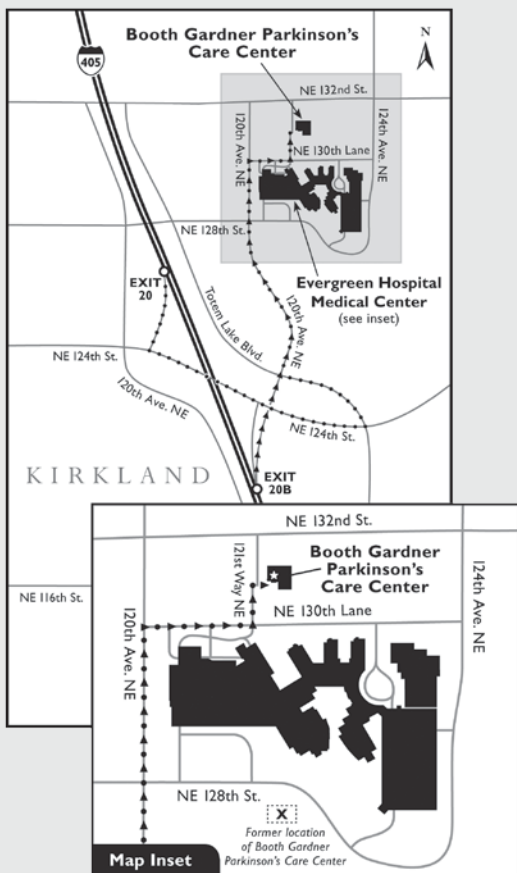
It's important to include wellness in the prescription for Parkinson's. With a wellness approach, the focus shifts from treating the disease to caring for the whole person.

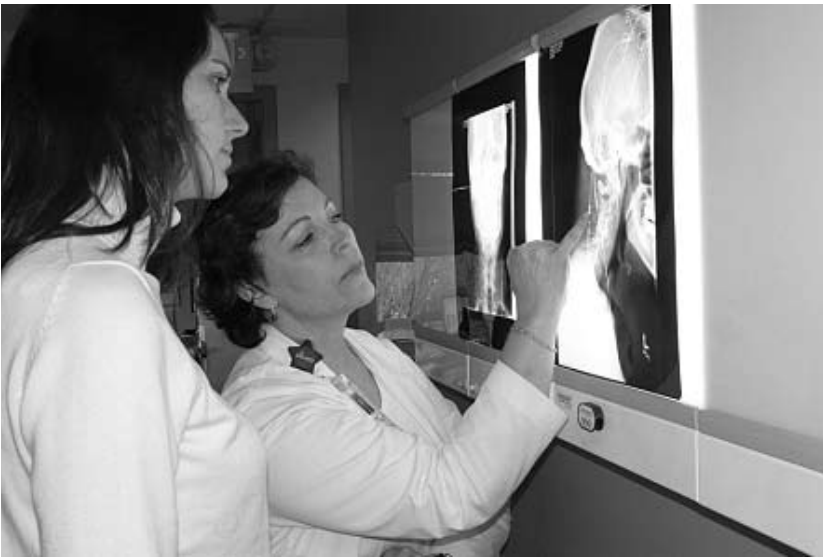
It's easy to feel overwhelmed by Parkinson's disease and to focus only on symptoms and problems. The goal of the Center's wellness program is to help patients manage stress, make healthy lifestyle changes, and gain a sense of empowerment and control.

Beyond the current wellness programs in communication and exercise, the Center's expanded wellness offerings include courses in disease self-management and in emotional, spiritual and physical well being.

GETTING THERE

The Booth Gardner Parkinson's Care Center is seeing patients in its new location at 13030 121st Way NE, Suite 203, Kirkland, WA 98034. Call 1.425.899.3123 or visit online at www.evergreenhealthcare.org/neurosciences/parkinson for directions.





Courtesy photos



These photos depict a day in the life of the Booth Gardner Parkinson's Care Center. Clockwise starting below: Administrative specialist Robert Brazzell reviews a process with medical receptionist Arsha Sharif. Physical therapist Ann Zylstra guides patient Tina Bell in a balance exercise. Dr. Alida Griffith assesses a patient's fine-motor skill. Speech and language pathologist Beth Edwards, left, and physical therapist Lisa Ireland review a head-and-neck X-ray of a patient who has had DBS surgery. Occupational therapist Kay Ballen gathers a patient's information in order to develop a treatment plan. From left, social worker Nancy Crute, medical assistant Aarti Chand and medical records clerk David Greenhow review a patient chart.



MEET THE PARKINSON'S TEAM

The clinical staff at the Booth Gardner Parkinson's Care Center comprises highly trained neurologists, neuropsychologists, and physical, occupational and speech therapists, all with expertise in Parkinson's disease.

Pictured to the right, from top to bottom, are: **Kay Ballen, OTR/L; Marilyn Borromeo-Wesner, ARNP; Nancy Crute, MSW; Evelyn Donascimento, PTA/L; Sierra Farris, MPAS, PA-C; Shirley Glazer, SLP; and Martha Glisky, Ph.D.** Second column: **Melissa Pei, PT; Ann Settles, COTA; Jeff Shaw, PsyD; research coordinator Cherrie Sia; Marjie Kay Thomas, CMA; Teresa Wilson, MA; and Ann Zylstra, PT.** For a bio about each clinical staff member, visit the Center online: www.evergreenhealthcare.org/neurosciences/parkinson

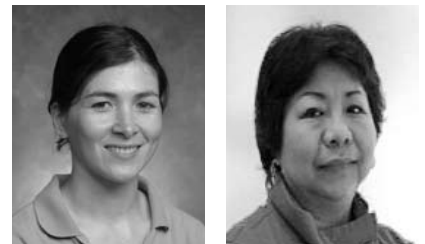
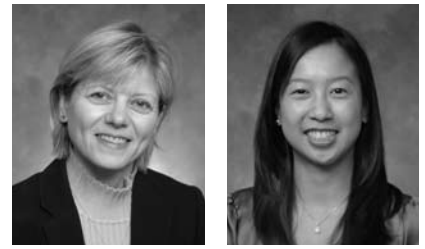
Monique L. Giroux, M.D., is medical director of the Booth Gardner Parkinson's Care Center. Before coming to the Center she was medical director of Outpatient Movement Disorders at the Cleveland Clinic in Ohio, where she established the Euclid Hospital Neurorehabilitation Program for Parkinson's and served as medical director for the National Parkinson Foundation Center of Excellence for Parkinson's disease. Giroux received her medical degree from The Ohio State University, completing her neurology residency at Yale and movement disorders fellowship at Emory University. Her care and research are focused on the development of interdisciplinary rehabilitation, team medicine and wellness for Parkinson's disease. Giroux has developed specialized neurorehabilitation programs for deep brain stimulation patients, Botox therapies, spasticity, and gait and balance. She is a recognized speaker in chronic illness and quality care models for Parkinson's.



Pinky Agarwal, M.D., is a board certified neurologist, fellowship-trained in movement disorders at The Neurological Institute at Columbia-Presbyterian Medical Center in New York. Her interests include Parkinson's disease; dystonia; essential tremor; restless leg syndrome; DBS for dystonia, tremor and Parkinson's disease; cerebellar ataxia; Huntington's disease; Botox injections for spasticity and dystonia; tic/Tourette's syndrome; and myoclonus. Agarwal has been the principal investigator on numerous clinical trials and was previously director of clinical research at The Colorado Neurological Institute.



Alida Griffith, M.D., is a movement disorders neurologist, fellowship-trained at Harvard-affiliated Beth Israel Deaconess Medical Center in Boston and a diplomate of the American Board of Psychiatry and Neurology. Her expertise includes Parkinson's disease and other movement disorders, patient selection for deep brain stimulation surgery, and post-surgical management of deep brain stimulators, as well as the administration of Botox injections for dystonia, blepharospasm and hemifacial spasm. Griffith is a principal investigator for clinical research trials at the Center.



Effective ‘freezing’ treatment takes a team

Clinician teams at the Booth Gardner Parkinson’s Care Center, focus on improving quality of life—one patient at a time.

One example of the Center’s team approach is its program to treat a common yet often disabling symptom of Parkinson’s disease—“freezing.” A freezing episode is a brief, involuntary inability to move that some describe as feeling like one’s feet are “stuck to the floor.”

Freezing impairs balance, increases the risk of falls, and can cause anxiety and embarrassment in social situations.

An array of factors can contribute to freezing. These might include disease progression, medications, physical strength, balance, vision, cognition and mood.

The good news is that many factors that contribute to freezing are treatable. And because there can be multiple contributing factors, the Center takes a multidisciplinary team approach to treatment, beginning with an assessment across five key areas:

Medications. The assessment of a patient’s medications is carried out by a physician, who is then able to recommend adjustments to dosage and timing. The rationale is that optimizing a patient’s “on” time through medication may reduce episodes of freezing.

Strength, range of motion, gait and balance. Assessment is carried out by a physical therapist, whose careful observation of patients can uncover physical factors contributing to freezing.

Home and environmental safety. An occupational therapist identifies any environmental factors that might be acting as triggers for freezing episodes. Household clutter, for example, is thought to be one visual cue for freezing.

Vision. Poor vision can impair balance and exacerbate freezing. An occupational therapist assesses patients’ vision to see if improvements can be made.

Cognitive and psychological factors. Because anxiety and cognitive impairment can contribute to freezing episodes, it is important to include an assessment by a neuropsychologist.

Based on the results of the full assessment, the “freezing team” is able to design a comprehensive intervention plan for each patient.

This plan may include a series of physical therapy sessions in which patients learn sensory strategies or “tricks” to free up the feet, along with exercises to improve strength and balance. Occupational therapists may assist patients with medication management. And a neuropsychologist may counsel in strategies for coping with anxiety.

By working as a team, clinicians are better able to understand the factors contributing to the symptoms and provide the most effective treatment program.

FROM THE MEDICAL DIRECTOR

As medical director of the Booth Gardner Parkinson’s Care Center, I believe a comprehensive approach to care—addressing the whole patient, not just treating the disease—is critical to the successful management of Parkinson’s disease.



In fact, it is this approach to care that fostered the Center’s significant early growth. There was then, and continues to be today, tremendous community response to comprehensive care for Parkinson’s disease.

An ongoing commitment to the Parkinson’s community, from both Evergreen Healthcare and our partner the Northwest Parkinson’s Foundation, is a strong framework that will benefit patients both locally and nationally as we work toward establishing best-care practices for Parkinson’s disease. Fulfilling this goal can only be accomplished with teamwork.

Advancing care for people with Parkinson’s disease requires a knowledgeable and creative team committed to improving quality of life for patients. The Booth Gardner Parkinson’s Care Center team is an exceptional group of professionals working together to better the lives of people with Parkinson’s.

Our team’s commitment to and belief in the importance of comprehensive care for people with Parkinson’s disease is the framework for the care and services we provide at the Booth Gardner Parkinson’s Care Center.

I look forward to the years ahead as we continue to challenge current models of care to improve the lives of patients.

Sincerely,

A handwritten signature in black ink that reads "Monique Giroux". The signature is written in a cursive, flowing style.

Monique L. Giroux, M.D.

New clinical programs geared to patients at a distance

At the Booth Gardner Parkinson's Care Center we have developed a care team dedicated to improving quality of life for Parkinson's patients. Our focus is better health and well being, and—perhaps most important—hope for people living with Parkinson's.

Our team members work side by side, all under one roof. The team includes movement disorder-trained neurologists, a physician assistant, nurses, a social worker, physical therapists, occupational therapists, a speech and swallowing therapist, and neuropsychologists.

In 2008 we introduced two new programs to meet the needs of patients who would benefit from comprehensive care but live too far from the Center for regular medical visits.

The Comprehensive Care Clinic

Our interdisciplinary team will work with you and your family to develop a holistic approach to your care, giving you the tools you need to do well, gain control, and make positive steps toward better quality of life.

This program is undertaken in two consecutive days during which our team thoroughly evaluates patient needs on Day 1 and develops a treatment plan to take home on Day 2.

Treatment is individualized. The team looks at all aspects of treatment, including movement and non-movement symptoms, cognition, mood, and physical and nutritional health.

Concerns or problems at work, at home or in the community are reviewed, as are steps to maintain your hobbies and relationships.

Goals for this program include:

- ◆ Promoting lifestyle changes and coping strategies that help patients live well and improve quality of life by taking charge of their Parkinson's disease.

- ◆ Educating care partners and family members.

- ◆ Reviewing and optimizing medical therapies.

- ◆ Identifying and treating physical, movement, home, work and communication problems.

- ◆ Developing an exercise program tailored to your needs and your Parkinson's disease to improve strength, endurance and independence, and help prevent future problems.

- ◆ Identifying and treating cognitive and mood problems such as depression, stress and anxiety. Treatment programs include medical therapy and non-medical treatment such as motor relaxation for stress reduction.

- ◆ Promoting patient safety by evaluating balance and the potential for falls.

- ◆ Using your own interests to guide therapy and encourage creativity shown to promote well being.

Deep Brain Stimulation Troubleshooting Clinic

Our second new program is a clinic for patients who are considering deep brain stimulation surgery but need more information, as well as those who are having trouble after DBS surgery.

This program offers individualized comprehensive evaluations for patients considering DBS or patients with DBS.

All patients are evaluated by a neurologist specialized in movement disorders and a nationally recognized DBS programmer and educator. When needed, patients see other members of our specialty team.

After your visit, you and your physician will receive a summary of our evaluation and recommendations. If additional programming is needed, a detailed plan will be sent to your local programmer.

For patients considering DBS, the Booth Gardner Parkinson's Care Center team does a full evaluation to determine if DBS surgery is a reasonable next step in treatment.

The evaluation includes neurological and neuropsychological examination, a detailed surgery overview, review of goals and limitations of surgery, and discussions about long-term care requirements and living with an implanted device.

Patients who have already had DBS surgery will benefit from our expertise as the team:

- ◆ Discusses long-term care
- ◆ Develops a battery check-up schedule
- ◆ Determines the effectiveness of stimulation
- ◆ Establishes the most effective stimulation settings
- ◆ Determines and eliminates stimulation side effects
- ◆ Investigates hardware problems
- ◆ Determines how much is too much stimulation
- ◆ Integrates our rehabilitation team to optimize function
- ◆ Reviews and optimizes medical therapies
- ◆ Reviews environmental and medical considerations living with DBS
- ◆ Coordinates referrals to DBS surgical centers and
- ◆ When needed, admits the patient to the Center's inpatient rehabilitation unit

For more information about either of these new programs, or about the Booth Gardner Parkinson's Care Center in general, call 425.899.3123 or visit www.evergreenhealthcare.org/neurosciences/parkinson/.

This article was provided by the Booth Gardner Parkinson's Care Center.



**NORTHWEST PARKINSON'S
FOUNDATION** 400 Mercer Street
Suite 401, Seattle, WA 98109-4641
1.877.980.7500 • www.nwpcf.org

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The Northwest Parkinson's Foundation is a cofounder and partner of the **Booth Gardner Parkinson's Care Center** (13030 121st Way NE, Kirkland, WA 98034). This comprehensive care facility is home to physicians, neuropsychologists, physical and occupational therapists, and speech pathologists, all specialists in working with Parkinson's patients. To make an appointment, call **425.899.3123**.

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Parkinson's educational resources free for patients and caregivers

The Northwest Parkinson's Foundation provides information and support at no charge to Parkinson's patients and their caregivers, family and friends.

Want to learn more? Start with our website — **www.nwpcf.org**—where you'll find a wealth of information about Parkinson's, along with listings of support groups, special events, educational programs, and much more.

We also provide free educational materials by mail. You may request the book, *HOPE: Four Keys to a Better Quality of Life for Parkinson's People*, as well as a booklet for caregivers and this bimonthly newsletter. Order them for yourself or for a loved one—at no charge.

Sign up for our free email update and receive the latest in news and information about Parkinson's each Friday in your email inbox.

To learn more or request materials, email us at info@nwpcf.org, call us at 877.980.7500 or complete and return the enclosed postage-paid postcard.