

I N S I D E

Dental care with Parkinson's | 2

When to see your doctor | 3

Special section: PD research | 4-5

Tribute gifts | 6-7

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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From left, Team Parkinson's 2009 members Paddy Downey, Zach Cross, Brett Tocher, and Holly Cristina are jubilant at the STP finish in Portland in July.

Miles add up to hope for many

BY ALECHA NEWBERN

The Northwest Parkinson's Foundation thanks members of Team Parkinson's 2009 who participated in the Group Health Seattle-to-Portland Bicycle Classic on July 11 and 12, not to mention the volunteers who helped along the way.

Most of our team members cycled the 204-mile STP route in two days, although 15 completed it in just one day.

Why do they do it? For a lot of great reasons. Four Team Parkinson's 2009 members have Parkinson's disease themselves. Others have parents, partners, siblings, and friends with Parkinson's.

Several ride simply to support the Northwest Parkinson's Foundation's

advocacy for the Parkinson's community.

These men and women ask their companies, family members, friends, and neighbors to sponsor them by making donations. These donations support Northwest Parkinson's Foundation programs and services—including educational materials, the *Parkinson's Post* newsletter, a content-rich website, an annual conference, and much more—enabling us to connect regularly with our more than 30,000 constituents.

But fund raising is the easy part. The training—and the ride itself—take real commitment.

The STP begins each year in the Husky Stadium parking lot at the University of Washington. Resting spots are along the route every 15 miles or so. The

> CONTINUED ON PAGE 8

Dental care needs extra focus with Parkinson's

By James M. Noble, M.D., M.S., C.P.H.

If you or a loved one is living with Parkinson's disease, you are surely aware of its complexities. Among these is one that is often overlooked by neurologists as well as people with Parkinson's—dental health.

Why is it so important to address dental health issues? Poor dental hygiene can affect nutrition and increase risk for stroke, cognitive impairment, and weight loss. Parkinson's often poses unique challenges in establishing and maintaining an effective dental treatment strategy. People of all ages with Parkinson's face similar challenges, but for those who are older, the problems can be especially serious.

The factors accounting for diminished dental care in Parkinson's are both physical and behavioral.

Physical barriers

The physical symptoms of Parkinson's present challenges both for daily home dental hygiene and periodic office examinations.

In 2000, David Kaplan, D.D.S., a retired Columbia University dentist, noted that in people with Parkinson's, "major components of oral hygiene and home care programs ... require muscle-eye coordination, digital dexterity, and tongue cheek-lip control. Tremor and the associated loss and/or lessening of the above faculties mitigate against effective oral hygiene procedures."

Indeed, because of poor motor function nearly half of people with Parkinson's have difficulty with their daily oral hygiene regimen.

For example, people with Parkinson's are less likely than others in their age group to clean their dentures daily.

Parkinson's symptoms such as tremor, rigidity, and abnormal posture may make a dentist's examination more difficult. Weakened swallowing ability can increase the risk of choking from some treatments typically used by dentists.



Additionally, people with Parkinson's disease who have been on medications like levodopa for several years may begin to develop dyskinesias, which can affect the jaw (where they are called oro-buccal dyskinesias) as well as teeth grinding, both of which may create problems during dental exams and at home.

People with Parkinson's may also experience dry mouth, which can contribute to or worsen chewing difficulties or denture discomfort.

Behavioral barriers

In addition to the motor-related difficulties associated with Parkinson's, there are behavioral changes that may negatively impact dental care.

These include apathy, depression, and forgetfulness, all of which may lead a person with Parkinson's to pay less attention to his or her daily dental health.

Other behavior changes can affect nutrition. For example, people with Parkinson's require greater caloric intake than those without Parkinson's, but some individuals will actually experience decreased appetite.

This problem, combined with poor dental hygiene, often leads to a tendency to avoid nutrient-rich foods, like vegetables, which require the ability to chew well. It can also lead some people to develop a "sweet tooth" which may put them at greater risk for cavities.

People with Parkinson's may also experience some level of cognitive impairment, ranging from mild to severe. This sometimes leads to a decline in the practice and effectiveness of many daily self-care routines, including dental hygiene.

People who experience cognitive changes may also be more likely to miss dental appointments and less likely to report dental pain to their caregivers or dentist, meaning problems may go unaddressed for too long.

There are early signs to look for if you are worried that your own dental care, or that of a loved one, is declining. These include infrequent tooth-brushing, difficulties rinsing during daily dental care, poor denture care, and trouble sitting through meals.

Strategies for improving dental care

Clearly, the sooner attention is given to preventive dental care, the better. So what can a person do to ensure Parkinson's disease does not stand in the way of good dental hygiene? Here are a few tips:

Maintaining dental care at home. Perhaps the simplest intervention is an electric toothbrush, which provides the fine and repetitive motions that protect teeth most effectively.

In some people with Parkinson's disease, "one-handed

> CONTINUED ON PAGE 7

View care providers as partners in health

Q: How often should I see my doctor?

A: Because Parkinson's disease is a chronic condition, it is helpful to partner with your healthcare providers to get the most out of each visit. How often you should be seen by your provider depends on your needs and symptoms.

Most people find it helpful to see their provider on a regular basis before symptoms worsen. For some this may mean twice a year and for others three or more times annually. Talk with your providers. Ask them how often you should return, what information is important for you to gather between visits, and what the goal is of future appointments.

It is important to see your provider if you are experiencing certain symptoms or if your symptoms worsen. Problems with balance and swallowing—as well as freezing, depression, hallucinations, and cognitive changes—can significantly impact your safety and quality of life. It is important to see your provider if these problems are new or if you are experiencing more difficulty with them. A referral can be made to a physical therapist, occupational therapist, or swallowing specialist.

Parkinson's disease progresses slowly. A fast or abrupt change in your movement symptoms or cognitive skills could be a sign of another medical problem that worsens how you feel with Parkinson's.

Parkinson's patients should have a primary doctor as well as a Parkinson's specialist. Your primary care provider (PCP) can evaluate you for the more common medical problems that lead to a worsening in Parkinson's, such as pneumonia, dehydration, or a bladder infection.

Your PCP will also manage other conditions of aging that can impact how you feel with Parkinson's. These include heart disease and stroke and their risk factors, as well as nutritional status and vitamin levels, bone density, anemia, and thyroid problems. Another important role for your PCP includes yearly skin



ASK THE EXPERT features questions from readers and responses from **Monique Giroux, M.D.**, medical director of the Booth Gardner Parkinson's Care Center in Kirkland, WA. Got a question? Email it to questions@nwpf.org, mail it to 400 Mercer Street, Suite 401 | Seattle, WA 98109-4641, or call us toll-free at 877.980.7500.

In responding, Dr. Giroux seeks advice from a variety of specialists. For this month's response, Dr. Giroux sought input from **Sierra Farris, MPAS, PA-C**, neurostimulation program coordinator at the Evergreen Neurological Institute in Kirkland, WA.

examinations since the skin cancer melanoma is more common in Parkinson's than the general community.

Sierra Farris, MPAS, PA-C, has a new patient clinic appointment at the Booth Gardner Parkinson's Care Center. During this visit, she

reviews patient-care expectations, strategies for self-care management, and tips for how to get the most out of your healthcare visits. She offers the following tips for getting optimal care:

- ◆ Ask your doctor how often you should come in for appointments. Establish expectations for follow-up visits, goals for the visit, and what to watch out for and report between visits.

- ◆ Do you feel more comfortable seeing your doctor for routine checkups every three to four months, or would you prefer to wait until symptoms have worsened? Some patients prefer to not go to the doctor if they are doing well; others prefer to see the doctor more often to stay on top of any changes in their Parkinson's. Talk to your doctor about the pros and cons of each approach.

- ◆ Ask your provider about symptoms you should monitor that will indicate you need to see the doctor. For instance, review the side effects of a new medicine. Ask what you should do if they occur and when would you need to schedule an earlier office visit.

When should you see your primary care physician? Your PCP is a vital member of your care team for Parkinson's and your general health. Your wellness with Parkinson's depends on your overall health. Be sure to see your PCP annually. Your PCP will also monitor other conditions that are important to your optimal health.

An abrupt change in symptoms could be a sign of another medical problem that worsens how you feel with Parkinson's.

Clinical trials a key step in drug approval

By **Susie Ro, M.D.**

A clinical trial is a medical research study involving human volunteers, intended to help answer specific questions about the effects of a new treatment on people, such as the safety and efficacy of new medications, treatments, or medical devices.



Other types of clinical trials include prevention trials, screening/diagnostic trials, genetic studies, and quality-of-life trials.

Clinical trials are conducted in four phases, each with a specific purpose.

Phase I: Is the drug/treatment safe? The new drug or treatment is tested in a small group of people (20 to 80) for the first time to evaluate its safety, determine a safe dosage range, and identify side effects.

Phase II: Is the drug/treatment effective? The study drug or treatment is given to a larger group of people (100 to 300) to see if it is effective and to further evaluate its safety.

Phase III: Is the drug/treatment better than nothing or available therapies, and do the benefits outweigh the risks? The new drug or treatment is given to large groups of people (1,000 to 3,000) over longer periods of time to confirm its effectiveness, monitor side effects, and compare it to standard therapies or a placebo (sugar pill).

Most of these trials are “blinded,” so that neither patients nor researchers know who is receiving which treatment, to ensure objectivity.

Phase IV: Can the drug/treatment be helpful for other conditions?

Why are clinical trials necessary and important? In the United States it is only through clinical trials that new medications and treatments can be approved for use—by the Food and Drug Administration. For this reason, participation in clinical trials is essential to getting new treatments available to patients.

Less than 1 percent of people with Parkinson’s currently participate in trials. If more people were to participate, trials could be completed at lower cost (freeing up funding for other things) and in a shorter amount of time (leading to quicker approval of new treatments).

Currently, trials may take anywhere from three to five years to get a new

If more people were to participate in clinical trials, research could be completed at lower cost and in a shorter amount of time.

treatment approved, and they are so expensive that they are usually funded by pharmaceutical companies.

There are clear benefits for those who participate in clinical trials. By seeking out cutting-edge therapies, participants gain access to new research treatments before they become widely available.

They can also play a role in furthering science and potentially helping other patients who could benefit from new treatments.

And participants can learn more about Parkinson’s and get care by leading healthcare professionals, often free of charge.

What are some positive results from recent clinic trials? Listed here are

the new Parkinson’s drugs made available through clinic trials over the past five years.

Azilect (Rasagiline)—This MAO-B inhibitor approved for early Parkinson’s may have disease-modifying properties.

Neupro (Rotigotine) patch—Patches allow for smooth, long-lasting effects, but these patches were recalled due to crystallization.

Parcopa—Orally disintegrating carbidopa/levodopa tablets

Requip XL—Once-a-day, long-acting dopamine agonist

Zelapar—Dissolving tabs; a reformulation of selegiline

Exelon patch—For Parkinson’s disease memory problems

The availability of these medications greatly enhances the options for management of Parkinson’s symptoms. Many more medications have been studied, but so far no other treatments

have passed Stage III trials.

However, even “negative” trials have given researchers valuable information about the nature of the disease and how to guide future trials in Parkinson’s.

The treatment options for Parkinson’s would not be available today without clinical trials and the people who volunteer to participate in them.

There are still many trials ongoing, many opportunities for patients to make a difference in the future—for themselves and for others with Parkinson’s.

Dr. Ro is a Parkinson’s specialist with Swedish Healthcare in Seattle.

HOPE conference to feature research and other topics

Research will be front and center at the fourth-annual HOPE Conference hosted by the American Parkinson Disease Association—Washington Chapter and the Northwest Parkinson's Foundation on Saturday, Nov. 7, at the Seattle Airport Hilton Hotel Conference Center.

Clinician-researcher James B. Leverenz, M.D., of the Veterans Affairs Puget Sound Health Care System and University of Washington will talk about the Pacific Northwest Udall Center, a new federally funded research site that will focus on cognitive changes in Parkinson's disease.

Another speaker will be J. William Langston, M.D., founder, CEO, and scientific director of the Parkinson's Institute in Sunnyvale, CA. Dr. Langston gained recognition in 1982 for the discovery of a link between a synthetic heroin and parkinsonism.

Other speakers will focus on a range of topics related to living well with Parkinson's. They include Laurie Mischley, N.D., of Seattle Integrative Medicine, author of *Natural Therapies for Parkinson's Disease*; Stephen M. Setter, PharmD, associate professor of pharmacotherapy at Washington State University, in a session titled "Parkinson's: The Role of Chicken Soup and Medications"; and John Argue, a San Francisco-based actor, director, and theater arts teacher who teaches movement and voice for people with Parkinson's.

Speakers will span a range of topics designed to help you think creatively about living well. Look for conference details—including a full list of speakers—in the next issue.

Opportunities are plentiful for taking part in research

By Ann Zylstra, PT

Any of us can participate in research, even those of us without Parkinson's. How better to compare normal aging to Parkinson's-related changes?

People can participate in research at many levels. Participation can be as simple as giving blood samples or sharing family health history. These acts can help in identifying causes of Parkinson's, a key step toward a cure.

Often research is looking for patterns, similarities, or commonalities. These patterns can direct other research projects. More complex research studies may include testing new medications for reducing symptoms or delaying the progression of symptoms.

One of many research opportunities at the Booth Gardner Parkinson's Care Center is our vision study. Occupational therapist Kay Ballen and I have been trying to come up with treatment strategies for *freezing*, a gait symptom often referred to as "sticky feet."

We have noted that on-medication freezing is most often associated with tight spaces or doorways, and rarely occurs on stairs except at the top and bottom. Strategies that help free up the feet include contrast tape stuck to the floor and other changes in visual input.

These observations, combined with substandard results of many vision tests done during clinic assessments, lead us to believe that freezing may be associated with impaired visual input to the brain. The only way to find out if this is true is through research.

There are no studies that address how Parkinson's might affect how the eyes work. Think about how with Parkinson's, muscle rigidity (stiffness) is generally greater on one side of the body than the other. Then consider how eye movements need the coordination of eight muscles per eye.

If one of the eye's muscles is more "rigid" or slower to react, the brain will get impaired visual input, or conflicting information. This can greatly affect vision in areas of perception (depth perception, peripheral field perception) and delay the speed of visual processing (the brain's ability to react to the information).

Typical eye exams assess visual acuity—focusing on how one is seeing, not how the eye is moving. If our hypothesis is correct, changes in eye function can impair mobility and other functional activities.

If we can confirm changes in eye function with Parkinson's, future studies will be to find out if we can improve vision in people with Parkinson's and to learn if improving vision also improves gait symptoms.

For more information about Booth Gardner Parkinson's Care Center studies, call 425.899.3126. To learn about other studies occurring in the Northwest, call the Washington Parkinson Disease Registry at 206.277.6080 or visit wpdr.washington.edu.

Ann Zylstra is a physical therapist with the Booth Gardner Parkinson's Care Center in Kirkland, WA.



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Gifts to the Northwest Parkinson's Foundation support educational resources including our website, email updates, caregiver booklet, newsletter, patient-education programs, and conference. Gifts also fuel outreach and advocacy on behalf of patients and families. We are privileged so many in the Northwest Parkinson's Foundation family support our mission by giving generously throughout the year.

We list tribute contributors in each Parkinson's Post. All donors are recognized in our annual Report to Contributors.

With a minimum donation of \$2,500, family members and friends can create a family fund in honor of a loved one. Gifts we receive through the creation of family funds will support general operations and be listed permanently in our newsletter and on our website. Contact Keri Kellerman at 877.980.7500 or kerik@nwpf.org to learn more.

Listed here are those who made tribute gifts from April 16 to June 15, 2009.

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> FROM PAGE 2

preventive strategies,” which allow a person to use the stronger side of his or her body, can also be helpful.

For instance, some find that caring for dentures is made easier by attaching a nailbrush to a household surface with a suction cup and then moving the denture back and forth across the brush.

Additionally, people with Parkinson's may find prescription-strength topical stannous fluoride gel treatments a good preventive strategy, both on a daily basis at home and during periodic visits to the dentist.

Stannous fluoride is often used in toothpastes to protect tooth enamel from cavities, but it is also available as a gel that can be directly applied to the mouth. Since this is a much stronger treatment than that found in toothpaste, a dentist should be consulted to recommend the dosage and frequency of use.

Mouthwashes are generally discouraged for people with Parkinson's because they present a choking risk, but in cases where they are still an option, it is best to look for those that are non-alcohol based and that use either chlorhexidine (an antiseptic) or baking soda.

A good alternative is a chlorhexidine brush, which is a swab laden with chlorhexidine that you can apply to your teeth. They are available only by prescription, so you will need to consult your dentist.

Improving dental visits. There are several ways people with Parkinson's and their caregivers can improve the value of their visits to the dentist, beginning with timing them strategically. For example, it is wise to plan for early morning visits, when waiting times tend to be shorter.

Additionally, it's best to take levodopa 60 to 90 minutes prior to the office visit to take advantage of a peak response period, which may improve the patient's ability to meet the demands of a dental exam.

Finally, it may help to plan a series of brief office visits rather than fewer, longer visits. As Parkinson's progresses, the amount of time during which a person responds optimally to Parkinson's drugs can shrink, so shorter visits may be more realistic and productive.

Considering medications and surgery. As Parkinson's progresses, motor symptoms worsen and anxiety may increase, making home dental care and routine dental work more difficult. A neurologist will often be able to help in such situations, weighing the risks of medications with the potential benefit of a dental intervention.

If invasive procedures, such as tooth restoration, are indicated, these should be undertaken as early as possible in Parkinson's progression, to minimize risk. If general anesthesia is required for a procedure, the patient should be warned that the recovery period for a person with Parkinson's may be prolonged.

This informal list of suggestions to improve oral health is not comprehensive, but it offers a framework for intervention based on the best available (albeit limited) data.

Thankfully, researchers with multidisciplinary interest are actively investigating links between neurologic and oral health. We hope their findings will lead to interventions that improve oral health in people with Parkinson's disease.

Dr. Noble is an assistant professor of neurology at Harlem Hospital Center Columbia University College of Physicians & Surgeons and at the Neurological Institute at Columbia University Medical Center.



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> FROM PAGE 1

lunch stop for two-day riders is in Spanaway, WA, about 55 miles from the starting line.

A group of Team Parkinson's volunteers prepared and served an amazing lunch spread. Also on hand this year were two message therapists and a bike mechanic—not to mention all-important shade and chairs for relaxing in.

The midway point for the STP is Centralia, WA—Mile 102. Here, our riders were greeted by Northwest Parkinson's Foundation staff and volunteers. From Centralia, our one-day riders kept on going to the Portland finish line, where another crew of volunteers enthusiastically greeted them.

Some two-day riders continued beyond Centralia before they checked in for the night, but many spent the night in Centralia. Early Sunday morning they started again, arriving in Lexington, WA (Mile 145), for lunch, then on to Portland for the finish line at Mile 204.

We had so much fun taking care of our Team Parkinson's riders and celebrating them along the journey—our way of saying thank you.