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A B O U T U S

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.

We welcome comments and inquiries regarding this newsletter and all our activities. Our contact information can be found on the last page of this newsletter. We look forward to hearing from you!



NORTHWEST
PARKINSON'S
FOUNDATION

200-mile bike trek is a family affair

By Joanna Glickler

When Chris Jewell crossed the finish line in Portland after a grueling two-day, 206-mile bicycle journey that began in Seattle, he wasn't thinking about himself or his Parkinson's. He was thinking about his two sons, 15-year-old Sam and 13-year-old Pat, who had just ridden alongside him in the 2004 Group Health Seattle-to-Portland Bicycle Classic (STP).

"One of the proudest moments of my life," Chris said, "was going across the finish line with both sons." It was Sam's second STP and Pat's first.

For the Jewells, the STP has become something of a family affair. On July 17 and 18, Chris was joined not just by his sons but by his brother Frank, who traveled from Atlanta to ride in the STP; his brother-in-law David Cameron; and his friend and neighbor Paul LaRussa, who began the STP tradition in 2001 by suggesting the ride.

Chris' wife, Suzanne Cameron, along with other family and friends, formed the support team and cheering squad that met the riders along the route and waited at the finish with welcome signs and open arms. "I cried when they crossed the finish line," said Suzanne, a board member of the Washington chapter of the American Parkinson's Disease Association and a self-described natural-born worrier. "Waiting for all three of my boys was very stressful for me," she said.



Photo by Scott Cameron

Chris Jewell is still smiling as he crosses the STP finish line in Portland, followed by family members Frank Jewell and David Cameron. That's wife Suzanne Cameron's enthusiastic wave in the foreground.

This was Chris Jewell's fourth STP and his third as part of Team Parkinson's, a growing group of riders who raise funds for the Northwest Parkinson's Foundation as they take part in the annual 8,000-rider STP. This year the Parkinson's team comprised 101 riders, several of whom, like Chris, have Parkinson's. Others ride to support a loved one.

Chris, 45, has always been active. Before his position with Seattle Parks and Recreation, he was a commercial crab fisherman in Alaska and later worked in construction, eventually managing projects. He began cycling in the late '80s, when he and Suzanne moved to Seattle to start their family.

With Parkinson's, Chris says, staying

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Addressing hallucination in Parkinson's people

By **Barbara Bisio, MC, LMHC**

Parkinson's people will tell you their lives are brimming with challenge—and that's no exaggeration. There are the disease symptoms themselves to contend with, and then there's the complication of managing the medications needed to address those symptoms.

And sometimes life is further complicated by side effects.

While medications can bring about remarkable positive change in the lives of Parkinson's people, helping them manage the day-to-day activities the disease makes more difficult, Parkinson's medications can also come with unwanted side effects.

One such side effect is visual hallucination, a term that refers to seeing things that are not real. By some estimates, between 10 and 40 percent of individuals with Parkinson's report experiencing visual hallucinations as a result of their medications.

Hallucinations may begin with vivid dreams and have been reported to take the form of small people, children and animals. Hallucinations don't have to be unpleasant.

Marjie Kay Thomas, medical assistant at the Booth Gardner Parkinson's Care Center, has known patients to have hallucinated "a house full of guests." On occasion, patients interact with their hallucinations, preparing meals for them and trying not to bump into them.

Another patient routinely hallucinated a nude woman sitting on his sofa. While the man was not bothered by this sight, his wife preferred the hallucination to be treated.

Unfortunately, the affected individual may be unable to tell the difference between a real or hallucinatory experience.

And untreated hallucinations can become a problem if the safety of the individual or others is at risk. Sometimes patients feel threatened by their hallucinations. People have been known to try to escape from or attack hallucinations, compromising safety in the process.

Cause and treatment

A chemical in the brain called dopamine is the key culprit in Parkinson's disease. When dopamine is in short supply, Parkinson's symptoms can appear, specifically movement problems such as tremor and rigidity.

In some cases, medication solves movement problems but delivers more dopamine than needed to parts of the brain. When this happens, brain cells become overactivated and the result can be visual hallucination.

When medications are thought to be the cause of

hallucinations, those medications can be reviewed and adjusted by the physician, and often the problem is solved. Sometimes a physician will prescribe an additional medication to help decrease or eliminate hallucinations.

Remember: Only under the direction and supervision of a physician should any changes be made to medications. Dosing changes or withdrawal of medications can cause serious problems.

The caregiver's role

Caregivers and family members can help when a person with Parkinson's is experiencing perceptual problems—first by notifying the patient's physician. In addition, you can help by creating an environment that inhibits hallucination. Here are some things to keep in mind:

Between 10 and 40 percent of individuals with Parkinson's report experiencing visual hallucinations as a result of their medications.

► Indoor lighting makes a big difference. "Sun-downing" refers to the appearance or worsening of hallucinations after dark, when lighting is dim and there are more shadows.

► Beware of reflections and the movement of light. Car headlights flashing through windows create movement that commonly triggers hallucinations. Cover or remove mirrors as necessary. Some have found that applying contact paper over mirrors creates a semi-permanent fix.

► A person prone to hallucination may also benefit from a little more or less stimulation. For example, when someone apt to hallucinate is left alone in a dim room, the lack of stimulation can promote hallucination. On the other hand, a trip to a bustling public space may trigger visual hallucinations due to the intensity of activity and sound.

► Keeping living spaces free of clutter and unnecessary items can help reduce the misinterpretations of the environment that are common in the hallucination-prone person. For instance, a blanket or a piece of clothing on a chair might be mistaken for a person. In addition, patterns in the fabrics of furniture and drapes can increase the chances of hallucination; solid colors are less likely to cause visual inaccuracies.

In addition to being mindful of some of these environmental "triggers" of hallucination, it is critical for caregivers to keep watch over loved ones, making sure they do no harm to themselves or others as a result of hallucinating.

—*Barbara Bisio is an intern at the Booth Gardner Parkinson's Care Center in Kirkland, WA, and a doctoral candidate in clinical psychology at Seattle Pacific University. Marjie Kay Thomas, medical assistant at the Center, contributed to this story.*

New drug offers hope for easing dyskinesia

By Katherine “Kitty” Anderson and Stephen M. Setter, PharmD

There is hope for relief from dyskinesia in Parkinson’s if follow-up studies substantiate the initial positive effects of a new drug called talampanel.

Parkinson’s people are typically well aware of the increased involuntary movements known as dyskinetic movements, or dyskinesia, that some experience when using medications containing levodopa, the active ingredient in Sinemet. Dyskinesia in Parkinson’s can be more disabling than the disease itself.

It is not uncommon for a Parkinson’s person to experience one part of the body as “frozen” while another part is in a state of tremor. Dopamine, glutamate and GABA are some of the key chemicals, or neurotransmitters, that act on brain cells to excite or slow their activity and coordinate movement. The coordinated “dance” of the neurochemicals in the brain is complicated. An imbalance in the number of cells or levels of neurochemicals disrupts the normal rhythm of muscular movement.

Dopamine was the initial neurochemical studied for its effects on movement. The loss of dopamine in Parkinson’s is treated with levodopa, a compound that is converted to dopamine in the brain. An excess of dopamine is thought to be the cause of dyskinesia.

Dopamine-producing cells in the substantia nigra area of the brain help coordinate movement. When 60 percent of these cells die, Parkinson’s symptoms appear. The remaining cells go into overdrive to compensate. This results in malfunction and leads to difficulty in performing intentional movements. It is thought this might be due to an excess of inhibitory or dampening currents in the brain. Tremor may be a result of an excess of excitatory currents.

A physician’s goal is to decrease the tremors without decreasing the patient’s

ability to perform movement. Amantadine is a drug often used in this situation. It works by blocking some of the actions of glutamate on NMDA receptors involved in regulating movement. Glutamate acts on two brain receptors, NMDA and AMPA, which are important in coordinating movement.

Talampanel is the first drug used in humans that blocks the AMPA receptor. Indications from a preliminary study point to the possibility that talampanel may have a major role in decreasing levodopa-induced dyskinesia.

Another possible benefit of talampanel’s ability to block glutamate at the AMPA receptor would be to slow the Parkinson’s-related dementia that develops in some patients.

Talampanel has shown promising effects in decreasing levodopa-caused dyskinesia in animal studies as well as in a study of 30 Parkinson’s patients in the United States. It is thought that overstimulation with glutamate is part of the underlying process that leads to the progression of Parkinson’s. With less glutamate on the brain’s “dance floor,” the freezing of movement, dyskinesia and dementia may be avoided.

Those who have had Parkinson’s for at least five years and experience disabling dyskinesia may qualify to take part in a study on the effects of talampanel. For more information, call us at 1.877.980.7500 or email info@nwpf.org.

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Sleepless? Restless leg syndrome can take its toll on quality of life

By Katherine “Kitty” Anderson and Stephen M. Setter, PharmD

An estimated 12 million Americans have been diagnosed with restless leg syndrome—RLS for short—a condition that affects some 20 percent of Parkinson’s people.

Also known as Ekbom’s syndrome, RLS is characterized by an unusual sensation in the calves or thighs.

Patients with RLS often describe feeling pins and needles, “crawling” skin, mild cramping and an urge to move their legs. These irritating symptoms occur when the legs are at rest but resolve with movement.

Because RLS can lead to insomnia, it can severely diminish quality of life. When RLS means sleeplessness, the resulting fatigue, irritability and even depression can affect a person’s ability to function at work and can disrupt personal and professional relationships.

RLS develops under a variety of conditions, and there is some evidence to suggest a genetic link.

Those most at risk are over 40, under intense stress, pregnant, anemic or suffering from nerve or circulation disorders.

It is not clear why RLS is so common in Parkinson’s people.

Medications used to treat RLS alter brain chemistry. Pramipexole (Mirapex) and ropinirole (Requip) are effective treatments. Anticonvulsants that have been used to treat RLS are carbamazepine (Tegretol) and gabapentin (Neurontin) when neuropathy is involved. Levodopa/carbidopa (Sinemet), the drug commonly used to treat Parkinson’s, is also used in the treatment of RLS.

—Kitty Anderson is a fourth-year PharmD student at Washington State University. Steve Setter is an assistant professor of pharmacotherapy at WSU.

From Page 1

active is absolutely essential. Since his diagnosis in late 1998, he has fended off many of the slowing-down effects of Parkinson's with exercise, which he says improves his balance and coordination and boosts his energy. He regularly bikes around his Seattle neighborhood, in addition to swimming laps with his sons.

"The STP is the benchmark in my fitness training," Chris said. "A lot of things go by the wayside, but each year the deadline of the STP forces me to forget whatever else is going on and concentrate on taking care of my body and doing whatever is needed to get in shape."

He is limited only by the number of hours in the day. "Everything you do takes more time when you have Parkinson's," said Chris, who can no longer squeeze in a daily bike ride because other things occupy so much more of his time than they once did. "I used to do four times what I do now."

The Parkinson's challenge

The STP is a challenge even for the rider who isn't also facing Parkinson's. But for the Parkinson's person, an endurance event can be a real test.

To help keep his symptoms in check, Chris adhered strictly to his drug regimen while on the road. But the medications only take you so far.

"You have no reserve," Chris said of the extra energy that goes into completing the STP with Parkinson's as your riding companion. Parkinson's people "have a finite amount of energy and a finite amount of dexterity. When you use as much as you need for the STP, you pay for days afterwards."

Chris was among half a dozen other Parkinson's riders on the team, including 57-year-old Gary Raymond of Seattle, who rode his first STP this year.



Photo by Suzanne Cameron



Photo by Gary Raymond

Above: The Jewell-Cameron clan at the end of Day 1 (from left), Sam Jewell, Paul LaRussa, David Cameron, Pat Jewell, Frank Jewell and Chris Jewell. At left: Gary Raymond proudly displays his STP finisher's badge atop his dislocated thumb.

Gary, a computer specialist at the University of Washington in Seattle, diagnosed himself with Parkinson's after reading a magazine article last summer, and his diagnosis was confirmed by a doctor shortly thereafter. He characterized his symptoms—which include micrographia (tiny handwriting), legs prone to cramping, and weakness in his hands—as mild.

"I signed up for the STP having no idea what I'd signed up for," Gary said laughing. He first heard about the event from a friend, and he later discovered the Northwest Parkinson's Foundation during an Internet search. He joined the Parkinson's team before he'd even purchased a bike.

Gary said he joined in part to let all his friends know about his diagnosis—"to get the story out all at once."

And he said he was amazed at the response from friends and family. "I have been moved by an outpouring of love," he said, remarking that he received pledges to his STP ride from complete strangers after friends shared Gary's story. "It has been an awesome emotional experience," he said.

Despite a mishap about 40 miles from the finish line that left him with a dislocated thumb, and despite enduring

two days of 90-plus-degree temperatures, Gary completed the STP. When offered a ride in a support vehicle after his injury he firmly declined, determined to finish on his own—even if it meant riding one-handed.

How does he feel about his accomplishment? "Pumped. I feel absolutely pumped about it. Every day I wake up and say, 'Wow, I did that.'"

But his modesty comes through. "I'm no athlete," Gary insisted. "If I can do it at age 57 with six weeks of training, anyone can if it's their goal."

He'll be back on his bike as soon as his hand heals, and he'll be back on the team next year, he says.

The Jewell clan will be back, too.

In fact, Chris Jewell wouldn't miss it. "Each year, as Parkinson's takes a little more control from me, my fight to be in shape for the STP becomes more and more important," he said.

And that very fact—that Chris Jewell continues to make this ride, joined by Gary Raymond and others with Parkinson's—is important to the thousands with this disease. It inspires all of us—with or without Parkinson's—to get up and try harder.

—*Joanna Glickler is development director at the Northwest Parkinson's Foundation.*

THE **h**elping PAGES

The Northwest Parkinson's Foundation would not exist without your support. We rely on donations to carry out our work. Donations support a range of programs and services to help Parkinson's people live well—including the high-quality specialty care of the Booth Gardner Parkinson's Care Center; a growing Parkinson's Telehealth Program serving people in rural communities; educational and support materials, such as the *Parkinson's Post*, a weekly email update, our website, the Parkinson's Educator, and the book, *H.O.P.E.*; and advocacy efforts toward funding for Parkinson's research. If Parkinson's has touched you or someone you care for, please consider supporting this work through a gift.

Those listed here gave between May 18 and July 31, 2004. Thank you, friends!

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Take this photo tour of the 2004 STP with Team Parkinson's. Clockwise from top...

1) Jen Holloway snapped a shot of her bike computer at a key moment toward the end of the first day.

2) From left, Thea Brabb, Kirk Hoover and Ann Zylstra are all smiles at the Portland finish line.

Photo by Kurt Zylstra

3) George Smith takes a much-needed breather.

Photo by Gary White

4) Sean Bethune, who completed all 206 miles of the STP in one day, appears to fly across the finish line.

Photo by Sandy Bethune

5) Jen Hobden has perhaps never been happier to see blueberries.

Photo by Jen Holloway

6) Gary Raymond at a rest stop.

Photo by Chris Ramerman

The 2004 team has raised more than \$90,000 to date in support of the Northwest Parkinson's Foundation.

Thank you, riders, donors and sponsors!

To see more photos of Team Parkinson's in action and to learn more about the team, visit www.nwpcf.org.

Donations are still being accepted toward this year's fund-raising effort. Give online over our secure server (www.nwpcf.org),

by phone toll-free at 1.877.980.7500, or by mail to NWPF, P.O. Box 56, Mercer Island, WA 98040. Just mention that your gift is for Team Parkinson's!



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Caregiver support group welcomes participants

Being a caregiver is very hard work—physically, mentally and emotionally. Sometimes having a group to share with and learn from can make all the difference in how we live our lives.

Parkinson's caregivers in the Seattle area are welcomed to join a support group led by Carin Mack, MSW, a knowledgeable Parkinson's advocate. The group meets the second Tuesday of each month at 1 p.m., with the exception of the August meeting, which is scheduled for the 31st. The group meets at University Congregational Church, 4515 16th Ave., near the University of Washington. Contact Carin at socialwrkr@earthlink.net or 206.230.0166 for more information.

Links to support groups in other areas can be found at www.nwpf.org.

Parkinson's specialists to address current topics at fall educational meeting

Parkinson's specialists from the Booth Gardner Parkinson's Care Center invite the public to an educational meeting to learn about advancements in disease and treatment knowledge.

The meeting will take place from 3:30 p.m. to 6 p.m. on Oct. 7 in the educational classrooms (TAN Area) of Evergreen Hospital and Medical Center, Kirkland, WA.

The meeting is free but registration is required. Call 425.899.3000 for details, registration and directions.

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