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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

ONE VOICE FOR MANY



Former Vice President Al Gore and Washington state Attorney General Christine Gregoire listen to Dennis Wright during a forum on stem-cell research on Oct. 8 in Seattle. Photo by Ken Lambert, The Seattle Times

Advocacy role fuels patient's hope

By Dennis Wright

My story is not unusual—well, not unusual if you are 40 years old and have just had “that conversation.” You know, the one featuring a somber-faced doctor telling you the Parkinson's facts of life.

I understood the words *chronic* and *degenerative* to have negative implications. The word *progressive* had always seemed like a good thing. The room grew colder as I heard the doctor say “Dennis, you don't have a brain tumor. You have an incurable progressive degenerative disease called Parkinson's.”

I will not kid you—the conversation didn't kick me into action. I wallowed in a funk for a couple years.

Eventually, I came to the realization that Parkinson's is not at all like falling off a cliff. To me, it's more like walking down a steep hill: You can stop along the trail and enjoy the view, even turning back up the hill a few steps. Still, gravity continues to pull you down the hill.

Nevertheless, what I really want to

say is that you and I have some control. I believe our actions can affect our current condition. We can help others and, over the long haul, live better lives ourselves.

Let's review what I have been doing to stay happy, healthy and optimistic. Look over my plan, incorporate what you can, and add your own energy. But know this: Just as you don't lose weight sitting down to a big bowl of ice cream and cookies, my plan does not include sitting still for long periods of time.

Keep moving

Physically, I have done many forms of exercise including aerobics, water aerobics, long brisk walks and yoga.

Yoga seems to work the best for me. It has been great for my balance. Numerous times I've begun to fall, only to catch myself by going into a yoga stance.

Whenever I feel low or stiff, I walk.

Do whatever you can do to stay physically active. Keep in mind that the old saying, “Use it or lose it,” means *you*.

Continued on Page 7

# Riboflavin, red meat and Parkinson's: Is there a connection?

By **Kathrynne Holden, M.S., R.D.**

In October 2003, Brazilian researchers published a study titled "High doses of riboflavin and the elimination of dietary red meat promote the recovery of some motor functions in Parkinson's disease patients."

Upon learning of this study, many folks with Parkinson's disease naturally wanted to know more. They asked, What foods and supplements were used or excluded? And could the diet be helpful for them? These are good questions that deserve a thoughtful response.

It's important to bear in mind this was a small study. Thirty-one subjects were enrolled, and only 19 remained for the entire six months the study was underway. Although the results are encouraging, it cannot yet be stated that following this study's plan will be helpful for all the millions of people with Parkinson's worldwide.

However, it is an important study and should be viewed with respect. Here are some reasons why:

- 1) All 31 people originally enrolled in the study were found to be deficient in riboflavin (vitamin B2), despite the fact that their usual diets contained plenty of riboflavin for normal human needs.
- 2) All 19 patients who completed six months of treatment showed improvement in standing, walking and balance during the first three months.
- 3) About two weeks after starting the treatment regimen, many subjects reported better sleep at night, better reasoning ability and less depression.

## How was the study conducted?

Thirty-one people, in all stages of Parkinson's and taking various Parkinson's medications or combinations of these medications, were initially enrolled in the study. Researchers questioned them about their usual dietary habits and determined they were getting adequate riboflavin.

In addition, researchers noted that those with Parkinson's ate more red meat on average than subjects in a control group. Upon testing, however, they learned that all 31 subjects had some degree of riboflavin deficiency.

The researchers prescribed the study subjects 30 milligrams of riboflavin three times daily, at eight-hour intervals, for a total of 90 milligrams per day.

The dosages were spaced throughout the day because a high dose of riboflavin given all at once is mostly excreted.

When riboflavin is given in smaller amounts throughout the day, absorption is increased. Because those with Parkinson's reported a higher intake of red meat than the control group, red meat was eliminated from their diets.

Of the 19 subjects who remained for the duration of the study, most reported feeling better after two or three weeks. Researchers measured their motor capacity each month and found that they showed significant improvement after three months; some continued to improve throughout the length of the study. Riboflavin status also rose to normal levels.

## Will this diet cure Parkinson's disease?

No, this is not a cure for Parkinson's. It also isn't yet known who might benefit from this diet.

But the results are encouraging and certainly worth discussing with your doctor.

I recommend you see your family doctor and request a laboratory test for riboflavin status first, to determine whether you are deficient. If so, that will be an incentive to discuss the diet further with your neurologist.

If your neurologist agrees that a trial is appropriate, you will need to eliminate all forms of beef, pork, mutton and goat. Poultry, fish, eggs, dairy products, nuts, seeds and legumes (dried beans and lentils) are excellent protein sources that can be included.

You will also need to take 30 milligrams of riboflavin three times daily in approximately eight-hour intervals. It can be difficult to find 30-milligram tablets of riboflavin. If your pharmacist cannot order this for you, you can obtain 50-milligram tablets, split some of them in half, and take 25 milligrams twice a day and 50 milligrams once a day, sticking to the eight-hour intervals.

If your doctor agrees you should try this plan, I suggest keeping a journal and noting carefully how you feel. A number of people reported improvement after starting this diet, but at least one person reported no benefit. It may be helpful to record your experience and report it to your neurologist.

If the diet improves your symptoms, you may find you need less medication. It's also possible you could develop dyskinesia—uncontrollable twisting movements—which is often a sign of overmedication. You will need to report this to your neurologist, who may opt to adjust your medications.

If new information becomes available, I will post it online on "Ask the Dietitian" at [www.parkinson.org](http://www.parkinson.org)

Here's to your good health!

—*Kathrynne Holden is a registered dietitian specializing in Parkinson's disease. She has authored the self-help books Eat Well, Stay Well with Parkinson's Disease; Cook Well, Stay Well with Parkinson's Disease; and Parkinson's Disease and Constipation. For information, visit [www.nutritioncanlivewith.com](http://www.nutritioncanlivewith.com) or call 1.877.565.2665.*

# New dopamine agonist will offer novel delivery

By **Stephen M. Setter, PharmD** and **Brandi Kimball, PharmD**

Rotigotine is a dopamine agonist medication currently under development by Schwarz Pharma. It will be marketed under the brand name Neupro® (rotigotine transdermal system) and will join other dopamine agonists that include pramipexole (Mirapex®) and ropinirole (Requip®).

Rotigotine is being studied for treatment of Parkinson's disease and restless leg syndrome.

What makes rotigotine different from pramipexole or ropinirole? The answer lies in the how is it delivered to the body. While pramipexole and ropinirole are taken orally, rotigotine is delivered through the skin in a transdermal patch not unlike nicotine patches used to help people quit smoking.

The patch will deliver rotigotine continuously through the skin into the

body to provide steady levels. This type of delivery system is called a continuous delivery system; it maintains constant levels of medication in the blood.

When medications are taken orally there is typically a predictable peak (high level) and trough (low level) of the medication in the bloodstream. Medications delivered via transdermal patch are more likely to deliver a consistent and continuous level that could prove beneficial to people with Parkinson's.

Avoiding peaks and troughs may help alleviate associated fluctuations in response to oral medications. Data demonstrate that supplying consistent drug levels to the brain may prevent or delay abnormal movements known as dyskinesia and decrease side effects.

In addition to providing more constant drug levels, transdermal delivery may benefit people with slower digestion. Transdermally delivered medications bypass the stomach and absorption is not dependent on stomach emptying times.

Currently the rotigotine patch is being studied as a once-daily patch that should be replaced every 24 hours. In a U.S. trial, rotigotine was used in patients

with advanced Parkinson's on stable levodopa therapy and was found to positively decrease "off" times without increasing the incidence of dyskinesia.

Effectiveness in people with early Parkinson's is also under investigation. As rotigotine moves forward along the U.S. Food and Drug Administration approval process, we'll keep you abreast of its progress.

—*Stephen Setter is an assistant professor of pharmacotherapy at Washington State University's College of Pharmacy. Brandi Kimball is a geriatric resident at WSU.*

## Drug shows promise in two clinical trials

Rasagiline mesylate taken once daily significantly improved symptoms of Parkinson's disease both as initial monotherapy in patients with early Parkinson's and as adjunct treatment to levodopa in moderate-to-advanced patients, the results of two clinical trials have shown.

"In both trials involving early and more advanced patients, treatment with rasagiline showed significant benefit on Parkinson's disease symptoms throughout the course of the disease," said Ira Shoulson, M.D., professor of neurology at the University of Rochester School of Medicine and principal investigator of the trials, in a press release.

"The demonstrated benefits, safety and ease of dosing suggest that rasagiline could be a promising new treatment for Parkinson's disease," Shoulson said.

Once the drug is approved by the U.S. Food and Drug Administration, the pharmaceutical companies Teva Neuroscience and Eisai will co-promote it in the United States under the name Agilect®.

—*Source: Eisai press release at [www.eisai.com](http://www.eisai.com)*

## Program assists with medication costs

Looking to cut costs on prescription medications? A new resource may be able to help.

RxHelpforWA is a program that connects qualified, low-income individuals with discount prescription drugs directly from pharmaceutical manufacturers, according to the program's website.

Rx4Washington assists by:

- ◆ Combining hundreds of programs offered federally and privately to obtain discounts on more than 1,000 of the most popular medications.

- ◆ Cutting through bureaucracy by going straight to pharmaceutical

manufacturers to get the best deal for patients in need.

- ◆ Targeting patients who have fallen through the cracks of the healthcare system, specifically elderly and low-income patients who cannot obtain medication through private or government insurance programs.

- ◆ Using one easily accessible website and toll-free phone number.

To determine eligibility, patients will be asked to answer 10 questions about citizenship, income, insurance status and medications used.

To learn more, contact RxHelpforWA at 1.877.923.6779 or [www.rxhelpforwa.org](http://www.rxhelpforwa.org).

# Rigor in Parkinson's studies protects you

By **Berta Leis, Ph.D., R.N.**

Have you wondered if the claims that nutritional supplements, massage, acupuncture or other treatments are effective against Parkinson's disease are true? Have you questioned the basis of such claims? If so, please read on. The purpose of this article is to protect your health and pocketbook by explaining the process that needs to be completed before claims can be made that a treatment is indeed effective against Parkinson's.

Determining if a treatment or drug is effective and safe for Parkinson's people requires a study conducted with *rigor*. Rigor refers to scrupulous attention to detail and strict adherence to systematic methods for the purpose of enhancing the credibility of study findings. Rigor ensures that the merits of a treatment are based on evidence rather than on wishful thinking.

Rigor is established by using research techniques including a control group, a double-blind approach, randomization, and repeatability.

In rigorous studies, one group of patients is given an experimental treatment, while another—the control group—is given a standard treatment for the disease or a placebo.

"Experimental" means that the study drug is currently being tested and is not yet approved for marketing in the United States by the Food and Drug Administration (FDA).

A placebo is a treatment or tablet that is very unlikely to have a beneficial effect, such as a sugar pill made to look like the study medication but not containing medicine.

Many patients report improvement while on a placebo. (*Placebo* is Latin for "I shall please.")

Jeff Shaw's article on the next page discusses this so-called "placebo effect" in more detail.

When patients who enter a study are randomized, this means they are selected by chance, like flipping a coin into one of the treatment groups. For example, if a study has only two treatment groups, one with the experimental drug and the other with standard treatment, the patient's chance of receiving the experimental drug or standard treatment will be equal.

Neither the patient nor the person evaluating you (the study doctor) will know which treatment group the patient has been assigned to or whether he or she is receiving the experimental drug, hence the term "double blind." Study doctors are kept "blind" to prevent them from subtly tipping off the subject.

In order to conclude that an experimental drug or treatment is effective, patients receiving the experimental drug or treatment must show far greater benefits than patients not receiving the experimental drug (the control group).

This outcome must be replicated in similar studies—hence the concept of repeatability, which means the study findings can be duplicated in subsequent studies for the purpose of determining if the earlier results can be supported.

Anecdotal accounts—that is, personal experiences and testimonials reporting that a treatment is beneficial—are an excellent starting point for an investigation. However, even numerous anecdotal accounts do not confirm that a drug or treatment is either effective or safe.

In order to establish efficacy and safety, several steps are needed.

For example, a study in which doctors and patients know which drug is being administered (open label) must be conducted to see if the drug is

effective in that disease. If preliminary studies show promising results, this justifies conducting further studies that employ control groups, randomization, etc., to determine efficacy and safety. Currently, duplication studies for Co-EnzymeQ-10 are needed to establish the efficacy of Co-EnzymeQ-10 in Parkinson's.

Clinical trials represent a sound testing ground for unapproved drugs. During these trials, a drug is administered to patients and is evaluated for its safety and effectiveness in treating, preventing or diagnosing a specific disease or condition. The results of this testing are instrumental in the approval or disapproval of a new drug by the FDA. The FDA provides consumers with information on prescription, generic and over-the-counter drug products. The FDA's web site is [www.fda.gov](http://www.fda.gov).

The FDA does not regulate nutritional supplements; however, the same rigorous standards introduced in this article apply to nutritional supplements.

Don't let the "modern-day peddler" feed on your hope and unload your pocketbook at the same time. Unless the peddler can direct you to published research that shows the treatment or product he or she is pushing has been rigorously tested, then there is not enough information available to make an informed decision about the product.

In summary, studies conducted with rigor are critical in determining if a treatment or drug is effective and safe. If these studies have not taken place, there is not enough information available to determine if the drug or treatment is effective or whether the drug or treatment is safe in the short and long term.

It is recommended that you wait until rigorous studies are completed to make an informed decision.

—*Berta Leis is a research specialist with the Booth Gardner Parkinson's Care Center in Kirkland, WA.*



**Dr. Berta Leis**

# Placebo effect points to power of positivity

By Jeff Shaw, Psy.D.

What if you could think your Parkinson's symptoms away? There is evidence you can, at least to some degree.

Most people with Parkinson's disease know firsthand that negative thoughts and stressful experiences can make their symptoms worse. Anxiety is clearly a factor in magnifying Parkinson's symptoms.

Being significantly depressed is also associated with a faster Parkinson's progression. One research study found that in a year, 67 percent of patients with major depression progressed to the next stage of Parkinson's, while only 20 percent of the patients who were not depressed progressed to the next stage. (Both groups were initially of the same level of disability.)

Being depressed is associated with a group of symptoms including low energy, sadness, and sleep and appetite disruption, but one of the central features of depression is negative, helpless or hopeless thinking. Counseling and psychotherapy can address negative thoughts, in part by helping patients balance anxiety and concern with alternate, more positive ways of viewing their situation.

But can positive thinking be utilized to improve your Parkinson's symptoms?

You may have heard about the woman with Parkinson's who agreed to participate in an experimental brain surgery involving the implantation of embryonic tissue—and that she benefited dramatically from the surgery. Prior to the surgery, this woman had not been physically active for several years, but during the year following the surgery she was able to resume activities such as hiking and even ice skating.

When this individual agreed to participate in the study, she was informed that 10 of the 20 people receiving the surgery would have a “sham” surgery, meaning that there would be no actual brain surgery. This sham surgery—technically a placebo—involved drilling only partially through the skull and faking the surgery so that she (and her doctors) would believe the surgery could have been conducted.

You may have guessed by now that her only medical treatment was a partial hole in the head. In this study the clinicians saw significant improvement over all the patients' pre-surgical baselines, even for those who had not had the brain surgery.

How does this happen? Is it that our beliefs about our

limitations hold us back? Does negative thinking prevent us from attaining our best performance? Does positive thinking change the way our brains function?

The answer to these questions is clearly “yes.” Studies with professional weightlifters has shown that individuals have markedly surpassed their personal best performances when they were deceived regarding the amount of weight they were lifting. If they thought the weight was lower than their highest lifted, they were much more successful. The opposite was also true; if it appeared they were lifting more than they ever had before, they were prone to fail—even with relatively modest weights.

So at what level do positive beliefs operate? In the October 2001 issue of *Scientific American*, an article on the placebo effect described how neurologists used a PET scan of the brain to estimate dopamine activity inside an area of the brain affected by Parkinson's disease. Half the patients were given a shot of apomorphine, a drug that mimics dopamine, and the other half were given a placebo shot of an inactive substance.

In this study, the individuals who received the placebo released as much dopamine as those who received the drug.

Endless studies evaluating medical treatments have found that the placebo effect is significant and must be factored in when determining a treatment's effectiveness.

As individuals, it benefits us to harness the healing powers the placebo offers; this process is certainly psychological in nature. The question we should all be asking ourselves is, “Do my thoughts and beliefs help or hurt my quality of life and functioning?” The next question should relate to the “how” of changing these thoughts and beliefs.

Cognitive behavioral therapy (CBT) addresses changing those thoughts and beliefs that tend to contribute to unnecessary and harmful anxieties, depression, hopelessness and helplessness. Much of the suffering that individuals endure is clearly optional, but these patterns are difficult to stop because we have practiced dysfunctional thought processes most of our lives. Practice makes permanent!

It is difficult for individuals to catch themselves in the process, because the beliefs are accepted as “truths.”

The CBT therapist helps to identify and replace these self-thoughts with more adaptive and objectively realistic self-statements and beliefs. Most mental health professionals practice CBT in counseling.

In interviewing a potential counselor or psychotherapist, ask the question, “How do you help people change?” Then determine if the answer fits with your philosophy of change.

Quite possibly with the right guidance, you'll gain some of the benefits associated with the placebo effect without having go through the medical treatment.

—Jeff Shaw is a clinical neuropsychologist with the Booth Gardner Parkinson's Care Center in Kirkland, WA.



Dr. Jeff Shaw

Dear Friends,

The Northwest Parkinson's Foundation would not exist without the support of a great many generous people whose donations sustain our work.

I hope *you'll* include the Northwest Parkinson's Foundation in your year-end giving. We've watched our constituency grow dramatically this year, and we're now providing services to more people than ever. This makes your support all the more important.

If Parkinson's has touched you or someone you care for, please consider supporting our work through a gift today. You'll find an envelope inside this issue for convenience in making your tax-deductible donation. Gifts must be received or postmarked by Dec. 31 to qualify for a 2004 tax deduction—so please don't delay!

Donations support programs and services that help Parkinson's people live well, including the high-quality care of the **Booth Gardner Parkinson's Care Center**; a growing **Parkinson's Telehealth Program** that reaches out to people in rural communities; educational and support materials like the **Parkinson's Post**, a weekly email update, the **Parkinson's Educator**, our website, and the book, **H.O.P.E.**; as well as advocacy efforts toward funding for Parkinson's research.

Thank you so much for considering a donation, and best wishes for a wonderful holiday season!

All my very best to you and yours,



Bill Bell, Executive Director

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Continued next page

## A SPECIAL THANKS



Val and Bob Megargel (far left and center) pose for a photo with Northwest Parkinson's Foundation Board Chairman Booth Gardner (second from left) and co-founders Bill Bell (second from far right) and Craig Howard (far right). The Megargels were representing the Home Instead Senior Care Foundation, which provided a \$25,000 grant to the Northwest Parkinson's Foundation for expanding the Parkinson's Telehealth Program. The program provides educational programming to a growing number of Parkinson's people in rural Northwest communities. Thank you, Home Instead Senior Care Foundation!

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Siloam Springs Veterinary Clinic

**In memory of Tom Owens**

Ms. S. C. Funabashi

**In memory of Alvin Warren**

Mr. and Mrs. Ronald Barrett

Continued from Page 1

### Keep learning

I try to keep informed of exciting new discoveries in Parkinson's disease.

It's easy to find new information on Parkinson's. The problem is keeping up with all the news, there is so much Parkinson's research going on.

This is good news. And good news makes me happy.

### Keep talking

Advocacy has been my not-so-secret weapon in my fight against Parkinson's.

Being an active volunteer gives me a good feeling. I feel like I have some control over my future. When an issue of importance is being discussed in the news, I welcome the opportunity to add my perspective. Advocacy is my long-term health insurance plan.

Parkinson's has gone from unknown and underfunded to becoming a part of our presidential election debate. More money means more research. Research cures disease. More research hastens our recovery.

Why wait 10 years for the next big breakthrough? I'd rather get better in three to five years.

Who controls how much money will be used for Parkinson's research? You and your friends do through your elected officials. And it involves more than the election process. Now that the elections are over, we must educate our leaders. They will work on our behalf, but we need to be heard.

Contact your elected officials, tell them your story, and help them to understand what they can do for us.

My years of thinking *somebody should do something* has grown into an understanding that *I* can be that someone doing something. And so can you.

By caring for myself and advocating for all of us, I've learned that *having* Parkinson's doesn't mean *submitting* to Parkinson's.

—Dennis Wright was diagnosed with Parkinson's disease in 1992. He is active in Parkinson's advocacy at the state and national levels. He lives in Issaquah, WA, where creating rustic furniture is one of his hobbies.



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## Parkinson's Action Network hosts advocacy events

The Parkinson's Action Network will host its 2005 Research and Education Forum & Public Policy Forum from Feb. 6 to 8 in Washington, D.C.

These events are an opportunity for Parkinson's advocates and others to educate themselves on the latest scientific advances in Parkinson's disease research and well as get to know others in the broader Parkinson's community. Advocates will learn skills for bringing renewed energy to their advocacy work.

For more information, including details on applying for a scholarship to attend the events, call 1.800.850.4726 or visit [www.parkinsonsaction.org](http://www.parkinsonsaction.org).

## New event to showcase best in scientific developments

A new event in the international Parkinson's community is scheduled for early 2006.

The World Parkinson Congress will showcase the most important developments in the world of Parkinson's disease, including causes, treatment, and quality of life for patients.

The goal of the Congress will be "to advance an all-encompassing approach to the treatment of Parkinson's by bringing together the full spectrum of those who serve the Parkinson's community" and patients, according to press materials.

To learn more, call 1.800.457.6676 or visit [www.worldpdcongress.org](http://www.worldpdcongress.org).

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