

A New Decade Brings Fresh Starts, Positive Changes, Renewed Hope

In 2010 you told us you needed more support for people with PD and their care partners, so we started a *PD Support Group* that meets the second Wednesday of each month at the Deaconess Health and Education Center.

Caregivers asked for help with the unique challenges a family caregiver faces, so we started the *Caregiver Support Group* that meets every fourth Wednesday in the PRC library.

These new groups were added to our already thriving Women with Parkinson's disease (*WWPD*) *Support Group* and therapeutic activity groups; the *Tremble Clefs* singers, and the *Dance for PD* movement group. In 2011 we are renewing our commitment to listening, and providing the most needed resources.

In 2011 Expect More:

Fun

- ▶ Dance for PD in Spokane, or learn how you can start a dance program where you live
- ▶ Sing with the Tremble Clefs or learn how to start a singing program

Communication

- ▶ A new and improved (and more accessible) website/blog
- ▶ More on-line information & less paper
- ▶ An emailed version of our newsletter
- ▶ A more comprehensive calendar

Support

- ▶ A new *Mentoring Program* for those recently diagnosed.
- ▶ Greater outreach to rural areas of WA, OR, ID, MT and AK
- ▶ A renewed emphasis on Young Onset YOPD)
- ▶ A stronger Deep Brain Stimulation (*DBS*) *Support Group*
- ▶ Better information to share in support groups
- ▶ Help with starting supports groups in your area

Education

- ▶ More books are being added to our library. Do you have a favorite to recommend?
- ▶ "Living with Parkinson's Disease" panel on April 15th at the WSU Riverpoint Campus
- ▶ *The Carnival of Wellness* on April 30.

Changes to the Board of Directors

Lindy Wood Swain, PharmD will replace Frank D. Cholaj, RPh, MBA as President. Frank has been a major asset and will continue to serve on the Board. We welcome Judi Sloane back to the Board. Several new members will be recruited in 2011. To see a full list of Board members and staff please visit our website.



Opportunities for Volunteers:

We're currently identifying projects that can be accomplished by groups or individuals either all at one time, or over an extended period, either from our office or from your home - wherever that may be. We welcome your suggestions, and your time as a volunteer!

For Spokane & Coeur D'Alene-area Volunteers:

- *Office support—including assembling large mailings and working on database projects.
- *Event support including our annual *Shakin' BUT NOT Stirred* martini night and silent auction fundraiser.

For all Volunteers:

Spread the word! Help us identify and contact pharmacies, primary care physicians, neurologists, long-term care facilities, and caregiving services in your area, and distribute packets of materials we've prepared to benefit Parkinson's patients and their families.

For Caregivers Everywhere

Using Google Groups we've created a safe place for family caregivers to share personal stories, struggles, tips and triumphs: every aspect of caregiving. You must be invited in order to join the group. Contact the PRC to join. Moderated by Linda Lysne., Spokane Caregiver Support Group leader.

- ▶ Only members can post messages, read the archives, view the members list, create pages and upload files. This group and its archives do not appear in public Google search results, or the directory.

Fun(d)raising 2011

Walt and Shirley Jakubowski are selling special Spokane Tremble Clefs mugs to raise funds for the popular singing group.



These quality mugs come in two sizes: the standard mug holds 12 oz and sells for \$8, and the 15 oz mug sells for \$10. They're dishwasher-safe, microwaveable, and can be used for any hot or cold liquid.

They are available at all Tremble Clefs singing sessions and at St Luke's Rehab before the monthly TeleHealth meetings. You can also email: Waltj@SpokaneParkinsons.org

Something in the Mail

You may have noticed that we're no longer including a donation request envelope your newsletter. Many folks already use their own envelope to send donations, others go to our website and click on the Donate button to use their credit card.

In March you'll be getting short a note asking to please consider the PRC as you're making plans for your charitable contributions for 2011. Then in the fall, before Thanksgiving, you'll receive another letter asking for your support.

We're Going to the Races in June

Mark your calendar for the weekend of June 3-5, 2011 when the SOCIETY OF VINTAGE RACING ENTHUSIASTS (SOVREN,) takes to the Spokane Raceway. SOVREN is now a major sponsor of the PRC. We'll tell you more in the next newsletter, and on our website.



"I can't always control my body the way I want to, and I can't control when I feel good or when I don't. I can control how willing I am to step up if somebody needs me." ~Michael J. Fox

Cougar **R_x** Corner

Can't Sit Still? Maybe it's Restless Legs Syndrome.

By Lindy Wood Swain, PharmD

Have you ever sat down in the afternoon or evening, tired after a long day and ready to relax, only to experience a strange and uncomfortable sensation in your legs? Do you find that the only way to make these awful feelings go away is to kick your legs or get up and walk around? If so, you might be one of the many people with a condition known as Restless Legs Syndrome, or RLS. People with RLS may describe those pesky sensations as "crawling, tingling, creeping, or pulling."

The cause of RLS is not known, but it does seem to run in families. About 10 to 12% of the general population suffers from RLS, but it is more common in people with Parkinson's disease (PD). RLS affects up to 20% of people with PD, or 1 out of every 5. Aside from PD, low levels of iron (iron

-deficient anemia), kidney problems, and diabetes may increase the risk of having RLS.

The following symptoms are always present in someone with RLS:

- ▶ Uncomfortable sensations with a strong urge to move the legs
- ▶ The sensations happen when you are resting (sitting or laying down)
- ▶ The sensations happen in the evening and/or night

There are no specific tests your healthcare provider can perform to diagnose RLS. Rather, doctors diagnose RLS based completely on the symptoms you describe.

If you think you may have RLS, talk to your healthcare provider. Most healthcare providers will draw your blood and check your iron level, since

this is one possible cause of RLS. If your iron is low, your doctor will probably try to figure out why and



then prescribe extra iron for you until your levels are normal. There are also medications for RLS. If you already take pramipexole (Mirapex), ropinirole (Requip), or carbidopa/levodopa (Sinemet), you will be

happy to know that these medications also treat RLS. Other medications that can be used for RLS are gabapentin (Neurontin), oxycodone (OxyIR, OxyContin), tramadol (Ultram), and some prescription sleep medicines. Aside from medicine, there are ways to treat RLS.

Exercising during the day may help prevent some RLS symptoms. Many people find that a warm bath or shower in the evening is helpful. Stretching your legs in the evening or massaging your arms and legs may also relieve the uncomfortable feeling. Activities that keep your mind busy, like a great book or lively conversation, tend to help RLS. Alcohol, nicotine (smoking), and caffeine can make RLS symptoms worse, so you should avoid these substances, especially in the afternoon and evening.

Sexuality and Parkinson's

...There is hope for the patient with Parkinson's disease in being able to restore sexuality, or improve problems

Our TeleHealth speaker in March will be Kristoffer Rhoads, Ph.D., Neuropsychologist and Director of the Memory Disorders Clinic at Virginia Mason Medical Center in Seattle. His topic will be Sexuality and Parkinson's. The following article is reprinted from WebMD as a starting point for thought and discussion.

*Parkinson's Disease and Sexual Problems:

Sexuality is an important part of every person's physical and mental health. When a healthy adult is diagnosed with Parkinson's disease, many aspects of their physical and mental well-being are often shaken including his or her sexuality.

Because sexuality plays a significant role in a healthy lifestyle, worries often surface for the patient when his or her sexual desires and needs change. With the onset of Parkinson's disease, the develop-

ment of sexual problems may be frustrating. However, there is hope for the patient with Parkinson's disease in being able to restore sexuality, or improve problems that may develop.

A doctor can help the patient decide on the best course of action to solve the problem and can suggest medications to help alleviate some of the symptoms that may develop.

Why Does Parkinson's Disease Affect Sexuality?

A lowered sexual drive or desire following the diagnosis of Parkinson's disease may be more of a side effect caused by depression than by the disease itself.

Many of the symptoms associated with Parkinson's disease are thought to be caused by lowered levels of dopamine in the brain -- a chemical that transmits messages from the brain's "relay center" to its nerve cells, enabling physical

movement. It is possible that the dopamine decrease may also cause a lessened drive or interest in sex.

What Other Symptoms Are Linked to Loss of Sex Drive?

While Parkinson's disease often causes tremors and rigidity that contribute to physical pain that could then make sex painful or uncomfortable, men with the disease often suffer from erectile dysfunction.

Because Parkinson's disease negatively impacts the central nervous system (brain and spinal cord), it may be difficult for a male to obtain an erection. The male body requires a series of nerve impulses in the brain, spinal cord and penis in order to have an erection.

Problems with these nerve impulses, such as might occur with Parkinson's disease, may result in erectile dysfunction. In addition, the blood circulation to the penis and

the muscles in the penis need to be healthy to produce a normal

erection. Problems with circulation or muscle function may also contribute to the erectile dysfunction.

Medications and Sexual Dysfunction

Depression medications. Since depression is a common cause of sexual dysfunction and also one of the most common side effects that Parkinson's disease patients may experience, medications are often prescribed. Antidepressants may also cause sexual problems.

If sexual symptoms such as decreased sex drive and/or erectile dysfunction are present, patients should seek help for these symptoms which may be treatable.



ational cause-and-effect sort of thing? (For instance, was the cat curled up around your ankle and you tripped over it?)

It could also be the result of a physiological condition such as dehydration that caused you to become disoriented. Perhaps a urinary tract infection or other infection weakened your body and made you dizzy. Your blood pressure may have dropped — sometimes a side effect of medications for Parkinson's or other conditions. Or was it a case of fainting or "blacking out"? All these problems may have led to the fall, and they each make sense to the one who fell.

What is a normal reaction after a fall?

As adults, the aftermath of a fall can be demoralizing and confusing, even life changing. Regrettably, the anxiety and fear surrounding the fall and the possibility that you might fall again can lead to loss of function. You may ask yourself, "I was doing so well, why did I fall now?" and this uncertainty can transfer to anything from inability to get out of the car, or off the couch, to a situation like my "wall test," causing dizziness, freezing, paralyzing episodes, festinating and propulsive running

gait patterns, or even feeling too dizzy or unsteady to go out.

The Wall Test

Even after 20 years, and hundreds of therapy sessions in my practice, I am often baffled when a patient can struggle to perform a seemingly easy balance exercise of standing against a wall.

With their hips and heels against the wall, occasionally a patient reports that the "wall test" causes a feeling of dizziness, blacking out, or feeling like they just can't do it because their "legs are giving out," and they need to sit down. Their blood pressure is normal and there was no precursor of their symptoms; it was just a simple balance test.

My own "ah-ha" moment came recently when I found that a Parkinson's patient — who'd had a situational fall — was doing something actively to cause the next fall.

My theory is that their normal fight-or-flight physiological response became magnified after the fall, thus creating a sinking, unsteady, uneasy and "dizzy" effect. This in turn caused the once-confident Parkinson's person to become increasingly cautious and overprotective.

Signs of an overprotective response

1. Overly shifting weight to one side
2. An increase in looking down towards the feet
3. Reaching for objects before you get to them
4. Looking at what you're about to sit down on, despite knowing it's there
5. Unsteady or sudden reactions to normal balance responses such as standing up from a low chair, or standing after sitting for a prolonged time
6. Pulling oneself up with the arms rather than rising with the legs

What to do

1. Realize the change, and remember that it's okay to be fearful or cautious — but not overly so, or for a prolonged time.
2. Find out and feel what you're doing that may be causing this fear or overly protective response.
3. Ask your family members, caregivers, therapists and doctors to assess your pre- and post-fall behavior.
4. Start reinforcing the strategies of good balance, posture, and confidence and the Rule of Opposites that I wrote about in last month's newsletter.

5. Start out with small challenges to your balance.

It's a good idea to avoid obstacles that overly challenge your balance, such as getting into tight spaces (like the laundry room). And watch out for the family pet.

Most of all, understand your fear, and your reaction, and seek out help immediately from your doctor or therapist after a fall. Try meditation, biofeedback, or yoga to re-center yourself. Don't wait and let fear and anxiety rob you of an active and enjoyable life.



Here's a trick...

Try this if one of your feet doesn't seem able to rise up from the floor due to freezing or weight shift. Start out sitting and tapping that foot as if listening to music. Better yet, go ahead and listen to music. It gives you rhythm as well as pacing and tempo, plus it takes your attention away from your balance, and makes moving easier. After successfully tapping, try marching; then march and kick like a Can-Can dancer.

You can do this in either a sitting or lying down position. If you're seated, try doing it without arm or back support by sitting on the front part of the seat to avoid the back and arm rests.

The PRC is a 501 (c) 3 charity that depends on donations from individuals for over half of our budget. Please donate today by sending your check to our secure mailbox:

Parkinson's Resource Center of Spokane
PMB 199, 1314 S. Grand Blvd., Suite 2
Spokane, WA 99202-1174

Donate online with any credit card: <http://www.SpokaneParkinsons.org>

If you itemize, your donation may be tax deductible!

TeleHealth Schedule

January 10

Lindy D. Wood Swain, PharmD & Joshua J. Neumiller, PharmD: *Take Charge of your Medications: How to Empower Yourself*

February 14

Barton "Bo" Cooke: *Gamma Knife for Parkinson's Tremor when DBS is Not an Option*

March 14

Kristoffer Rhoads, PhD: *Sexuality and Parkinson's*

Our Mission: serving to enhance the quality of life of people affected by Parkinson's disease through empowerment, education, and awareness.

Contact us:

Parkinson's Resource Centre of Spokane
 910 W 5th Ave., Ste 256
 Spokane, WA 99204
 Phone: 509-473-2490 / Fax: 509-473-2495
 Email: Center@SpokaneParkinsons.org

We have a New Look



Our logo has been updated to fit the needs of our electronic age. You can now find us on Twitter, Facebook, and our blog; www.SpokaneParkinsons.org



Non-Profit
 Organization
 U.S. Postage
 PAID
 Spokane, WA
 Permit #28

What's happening where you are?

Do you have news or a story to share? We'd like know about support groups and activities outside the Spokane area. Is there something you want to learn more about? A program you want to start in your area? Please contact us and let's discover how we can work together to make a real difference in the lives of people affected by Parkinson's disease.

ASK the Physical Therapist

"Fear Factor"

The Anxiety and Fear After a Fall

When we were kids we spun, climbed, tumbled, dove headlong into leaves or snow, and did who knows what else in order to hit the ground. We got up easily most times, laughing with great glee and did it all again.

Then we grew taller and more mature, and we lost this natural aspect of youth. It was a lot less painful to hit the ground when we were 2 or 3 feet tall!

As an adult, a fall can lead to anxiety for your spouse and care-

givers, as well as issues ranging from embarrassment to catastrophic injuries, fractures, and even death. Falls in the elderly are the main reasons for nursing home placements.

What's more, you don't have to actually fall to be afraid of falling. The fear of falling, and the resulting anxiety, can cause you to become overprotective, either consciously or unconsciously.

Unfortunately the likelihood of falling is a natural part of the Park-

inson's disease movement disorder. It's normal and okay to be afraid, anxious, and downright spooked about falling. But what can you do?

Should you use an assistance device?

Sometimes, as a person ages, doctors and/or family members insist that the person use a cane, walker, or power chair to prevent a fall. While it is not necessarily bad to use an assistance device, it is critically important to use your balance skills rather than your hands as a stabilizing force. Your hands are for feeling and doing daily activities, not to hold you up!

With Parkinson's patients, it is imperative that they seek out help

to increase their balance and confidence in order to maximize their posture. An upright position and

arm swing is important for normal walking speed. Remember that any use of a device to aid in balance is a true "crutch" and you will still require treatment by your physical therapist, and follow-up.

Why did you fall?

If you've fallen, first we need to ask what the reason was for the fall. Was it an accident, or a situ-



Len Norfleet, PT