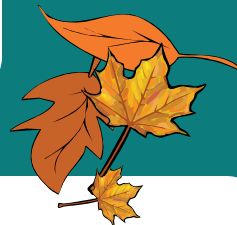


# MOVING FORWARD

**PMDC**

Plummer Movement Disorders Center

A National Parkinson Foundation Care Center



FALL 2008

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## PD News

**GlaxoSmithKline** has announced the availability of REQUIP® XL™ (ropinirole once-daily extended-release tablets) for the treatment of the signs and symptoms of Parkinson Disease. REQUIP XL is the first and only once-daily oral dopamine agonist indicated for PD.

Patients with Parkinson's disease may experience what is commonly known as "off" time when their medication wears off and their symptoms return. Symptoms such as slowness of movement, tremor, and rigidity can be problematic for these patients, causing simple activities and movement to become difficult. Results from a pivotal efficacy and safety trial showed that adding *Requip XL* to patients' existing levodopa (L-dopa) therapy reduced the amount of "off" time experienced by patients with Parkinson's disease by 2.1 hours per day on average, compared with baseline.

*Requip XL* provides continuous delivery of ropinirole over 24 hours to provide smoother blood levels without the peaks and troughs that multiple daily doses typically deliver. It is an important once-daily treatment option for patients with Parkinson's disease.

It's important to know that

1. This is a very easy drug to take that offers simple, once-daily dosing
2. It may be taken alone or in combination with L-dopa
3. REQUIP XL can improve symptom control in both early and late-stage PD

It's also important to know that this prescription is not for everyone. As with every drug, there is a list of possible side effects, and those need to be discussed with your doctor.

The drug company offers a number of patient assistance programs. For information on assistance for those who don't have prescription drug coverage, they have a website to visit or a phone number to call. The website is [www.GSKforYou.com](http://www.GSKforYou.com) and the phone number is 1.866.GSK.for.U (866.475.3678).

If you have questions or need additional information about GlaxoSmithKline's REQUIP XL, please call the GlaxoSmithKline Response Center at 1.888.825.5249 or visit [www.REQUIPXL.COM](http://www.REQUIPXL.COM).



I got tired of looking at all those leaves in my yard, so I went into action.

I closed the curtains.





## Driving and Transportation Safety: From an article in Caregiver Magazine by Ryan Mackey

Transportation can be an obstacle for many older people, and adjusting to either public transportation or rides from family is not easy. It is usually up to the family of the loved one who must handle transportation issues, and ensure they stay safe when on the roads. Here are some points to consider when assessing your loved one's ability to continue driving safely, or if needed, possible alternative modes of transportation.

- Assess your own feelings about older drivers in general, and see if you need to be a bit more understanding with their abilities when behind the wheel.
- Get a better idea about the driving skills of your relative by driving with him or her, or checking to see if they have had any traffic infractions recently.
- Be very observant to their driving habits and overall handling of the vehicle.
- Do not critique your loved one's driving - instead continue to support and reassure remaining capabilities.
- If you fear they have lost the ability to properly handle driving all the time, describe some viable alternatives such as driving during the day, and only driving on local streets.
- Have your loved one's vehicle checked routinely for general maintenance.
- If you find they are lacking in a certain area, there are driving programs available that can assist them in creating a better driving approach.
- Establish some better routines for your relative to follow, such as planning the route before going anywhere, or ensuring that the weather will remain "driver friendly."
- If you feel your loved one can no longer drive safely, please notify your PD health care provider.

## Parkinson's Disease National Registry - Don't be silent - sign up soon

The Muhammad Ali Parkinson Center at St Joseph's Hospital and Medical Center's Barrow Neurological Institute in Phoenix, AZ, is developing a national registry for people with Parkinson's Disease. It will be used to facilitate the development of new therapies and healthcare services to improve the quality of life for people with PD. Your active participation in the Registry will keep you informed of the current PD research and accelerate the process of informing you of research projects for which you may be eligible. The objectives are to track the functional abilities and cost of illness for people with PD over time, to assist the PD medical community with the development of recommendations for monitoring their patients and reports on patient outcomes to optimize patient care, and to assess characteristics of PD and treatment patterns.

\*Participation in the Registry is voluntary, confidential and free of charge.

\*You will be notified of clinical trials for which you may be eligible, however you are not obligated to enter the trials.

\*You will be asked to complete an updated questionnaire every six months.

\*The data you provide will be used in scientific publications in summary form only.

\*Information you provide will not be available to anyone without your permission.

\*Your name will not be released to any individuals outside the Registry management team without your written authorization, nor will it be sold for advertising or fund raising.

If you are interested, you may enroll online at: <http://www.parkinsonregistry.com> or you may write to:

CHW

St. Joseph's Hospital & Medical Center

Barrow Neurological Institute

Patient Registry for Parkinson's Disease

500 West Thomas Rd, Suite 720

Phoenix AZ 85013-4423



**Brain Games:** Parkinson's Disease affects your mind as well as your body. Your brain is just like your muscles — use it or lose it. Word games like Scrabble, crossword puzzles, and Word Finds help keep your brain active. On page 5 you'll find this issue's game. Do some aerobics with your brain.

## Director's Corner

by Dr. Elmyra Encarnacion, M.D., Medical Director of the PMDC

Let's talk about it....

### Genetics

The study of genetics in Parkinson's disease has expanded the last decade and has aided our understanding of the disease mechanisms. A majority of the cases are considered sporadic. Conversely, a minority of cases has been linked to genes --- much less than a quarter! The first gene was identified in 1997. To date, five genes have already been identified. The most recent discovery is the LRRK2 gene mutation, found to be the most common cause of familial PD and also a common cause of sporadic cases. Quite interestingly, sporadic and genetic cases similarly present with tremor, rigidity, bradykinesia and responsiveness to levodopa!



It has been accepted that there is a slightly increased risk

of PD in first degree relatives, but the interaction between environment and genes has been the general consensus. For example, those with genetic susceptibility (or family history), who are exposed to environmental triggers would develop the disease, but more evidence is needed to support this.

Should genetic testing, then, be routinely obtained? The answer is no, although some families would "just like to know". The truth is, genetic testing can be obtained commercially but is not routinely recommended in clinical practice since the reliability of the results is uncertain. Clinical practicality is questionable, since results, positive or negative, will not change treatment. Nevertheless, genetics will undoubtedly continue to unlock the mysteries of the disease and hopefully lead to translation that would result in more effective therapies...**and the excitement continues!**

**The autumn leaves are a lot like raising kids. First they turn on you, and then they fly away.**

**And next thing you know, you look out the window and they're back!**



## Manager's Corner

by Pat Simpson - MHSM, BSN, RN, Manager PMDC

Do you look forward to the change of seasons as much as I do each year? Fall brings cooler temperatures, beautiful foliage – orange, red, yellow leaves and flowers, excitement as football season begins again, and anticipation of holiday celebrations. Change can be good.

The PMDC is going through a period of time where changes are occurring that directly affect the Center's programs and the services we are able to offer our patients. We applied for grant funding again from the National Parkinson Foundation this past March, and after four years of granting us funding to start and support our programs, our request was declined this year. NPF has added new Centers and the grant application process has become very competitive. We are grateful for the four years they supported us, but are moving on now to seek other avenues of revenue. We are pleased to report that Scott & White has agreed to help fund staffing for the PMDC so we can continue to provide education and support for each of you. We continue to write grants to other entities and have formed a Fundraising Committee to help raise the funds needed to support your programs (i.e. educational symposiums, healthcare provider education, newsletter, support group

organization/programs and facilitator training, community health fairs, just to name a few). The new PMDC Fundraising Committee is really excited and working on an event for March that is going to be a ball! As soon as we have the date confirmed we will send out a notice to everyone, because this is an event you are not going to want to miss! Watch for details coming soon and mark your calendars.

A few weeks ago I read in a church newsletter that while most people don't like change, without change there is no improvement. The PMDC staff has accepted the challenge of change and is excited about the future of the Center. Your support is greatly appreciated. God bless you. Pat



Kathleen Brown, Carol Jonas-Simons, Cheriea Brim, and Pat Simpson help out the Freddie Powers Parkinson's Organization at Willie's Place over the 4th of July weekend.

## Tips from the Pros

**Social Work** by **Shelley Imholte**, LMSW, 254.724.5309

**R**emember when....

“Fall down, go BOOM” was cute to say? Falling can cause both serious physical injuries and psychological fears. According to AARP, falls are the leading cause of death among persons 65 years or older ([www.AARP.org](http://www.AARP.org)). The psychological fear of falling, especially for individuals who have had one fall, may limit their activities because of the fear of falling again. This is often the beginning of a downward spiral. Activity is then restricted in an attempt to prevent falling when in actuality limiting activity increases the risk of falling and injury. Falls increase when there is a lack of exercise and daily physical activity. Other causes for falls include: poor vision, dizziness, weakness, and arthritis. Persons with PD may experience



‘freezing’, sudden loss of blood pressure (orthostatic hypotension), and dyskinesias which can contribute to falls. As PD progresses it is likely that mobility will change as well. Paying attention to your symptoms and sharing them with

your physician is key to taking care of yourself!!

What can you do to avoid going ‘boom’???

- Pay attention to each movement you make. Do NOT do two things at once.
- Allow just a few minutes of sitting on the side of the bed before getting out of bed.
- Lift your feet as you walk and put your heel down first.
- Walk with a wider stance and swing your arms to help with balance.
- Avoid carrying items in your hands when walking.
- Do NOT walk in the dark. Use sensor nightlights!
- Avoid shoes with high-grip soles and high heels.
- KNOW your limitations and FOLLOW your instincts.

## Occupational/Physical/Speech Therapy



### I’m Falling for You! NOT!

Last month we talked about different forms of exercise, starting with Pilates. This month we explore Tai Chi. In only 1 search on PubMed there were 164 articles on Tai Chi and balance and mobility in people with Parkinson’s Disease. Following is one of the studies by ME Hackney & GM Earhart, of the Program in Physical Therapy, Washington University School of Medicine, St. Louis, MO 63108.

This pilot study examines the effects of Tai Chi on balance, gait and mobility in people with PD. Thirty-three people with PD were randomly assigned to either a Tai Chi group or a control group. The Tai Chi group participated in 20 1-hour long training sessions completed within 10-13 weeks; whereas, the control group had two testing sessions between 10 and 13 weeks apart without interposed training. The Tai Chi group improved more than the control group on the Berg Balance Scale, UPDRS, Timed Up and Go, tandem stance test, six-minute

walk, and backward walking. Neither group improved in forward walking or the one leg stance test. All Tai Chi participants reported satisfaction with the program and improvements in well-being. Tai Chi appears to be an appropriate, safe and effective form of exercise for some individuals with mild-moderately severe PD.

A wonderful resource that is based on Tai Chi movements is John Argue’s book and video, **Parkinson’s Disease & the Art of Moving**, ISBN #15722 4183-7, which contains a detailed presentation of **The John Argue Method**. This is “an ARTFUL approach to movement for people with PD that theoretically addresses the underlying motor control deficits associated with PD.” People with PD will find a comprehensive exercise program. There are also numerous helpful suggestions for dealing with specific problems like falling, freezing, or turning. The book can be found or ordered at most local or online bookstores. We have one copy in our PMDC PD library available for checkout.



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**Brain Games:** words can be found forward, backward, up or down, or diagonally. Have fun. Answers below, but don't peek!!



ACORN	EQUINOX	NOVEMBER	SEPTEMBER
APPLE	FALL	OCTOBER	SHORTER DAYS
BIRD MIGRATION	FARMING	ORANGE LEAVES	SQUASH
BLOWING LEAVES	FEAST	PIE	SWEET POTATOES
BLUSTERY DAY	FROST	PUMPKIN	THANKSGIVING
CANNING	HALLOWEEN	RAKE	TURKEY
CHESTNUTS	HARVEST	RED LEAVES	WINDY
CHILLY	HAYSTACK	SCARECROW	YELLOW LEAVES
COLD	HICKORY NUTS	SCHOOL	
CROPS	LONGER NIGHTS	SEASON	

**Music and PD** by Kathleen Brown, BMed, MT- BC/Community Outreach Liaison 254.724.6414



Ever thought about how much exercise a symphony conductor gets? In studies carried out by the life insurance industry, it was found that symphony conductors have a lower-than-average rate of mortality. And in an article in the New York Times “way

back” in December 1978 it was reported that “music may have charms little considered even by the poets who write so much about it or the musicians who create it. Under the right circumstances, a life devoted to music may be a prescription for longevity.”

An associate professor of medicine at the University of California, San Diego, also a symphony devotee and amateur musician did a little research on the longevity of symphony conductors. Compiling a list of 35 deceased major symphony leaders he found their mean length of life to be 73.4 years. The life expectancy of American men at the time he did his compilation was 68.5 years.

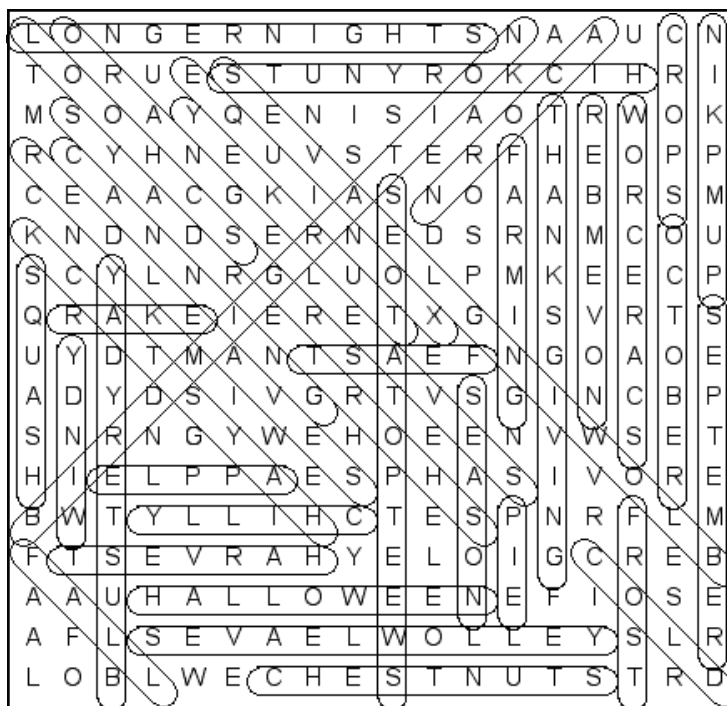
We can all benefit from this information. I discovered a fantastic program on the internet – it’s called **Conductorcise** ([www.conductorcise.com](http://www.conductorcise.com)). Maybe we can get its founder, Maestro David Dworkin, to come to the Central Texas area next Spring to demonstrate for us. The Maestro, as his website says, “has led orchestras across the country and abroad, and began his career playing the clarinet.” He wrote to me, “I have such a passion for the program and

have experienced some magical moments with people all over the country, that I am encouraged to never give up my goals of joy, health, happiness and compassion and the magic of music.”

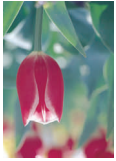


The beauty of it is that you don’t have to be a musician or a conductor, and you don’t need any special clothes or shoes to benefit – just put on your favorite music and “become” a world-famous conductor yourself!

*As the American Senior Fitness Association says, “Here is one physical exercise program that is innovative, unique, and truly special.”*



**Brain Game Answers**



The Dr. James Parkinson Tulip

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**The Plummer Movement Disorders Center** promotes quality of life for persons with Parkinson's Disease and their care partners. Gifts support educational programming such as our Annual PD Community Symposium, PD 101 class for newly diagnosed patients and their spouses and/or care partners, purchase of educational materials and this newsletter. By giving, you can also help support our Parkinson's outreach and advocacy efforts on behalf of patients and families. **If the work of the Plummer Movement Disorders Center has made a difference for you or someone you care for, please consider making a donation today.**

I would like to help with the work of the **Plummer Movement Disorders Center** at Scott & White Hospital with a gift of \$\_\_\_\_\_.

In Honor Of \_\_\_\_\_

In Memory Of \_\_\_\_\_

Please make your check payable to: Scott & White, Plummer Movement Disorders Center, and return it with this form to: 2410 S 31st St, Attn: Patricia Simpson, R&E/5 W Circle, Temple, TX 76508.

Please use my gift for:

- Outreach and Educational Programs
- Patient Services
- Research
- Area of Greatest Need