# #PARKINSONIAN

NORTHWEST PADRECC/Parkinson's Disease Research, Education & Clinical Center

# **ASK THE EXPERTS**

# YOUR QUESTIONS ANSWERED FROM OUR ANNUAL SYMPOSIUM



Dr. Marian Livingston is a Special Fellow in the neurological specialty of Movement Disorders at the VA Portland Health Care System (VAPORHCS, formerly the Portland VA Medical Center) and Oregon Health & Science University (OHSU).

If a Patient's natural aversion to drugs is very strong, at what point does it become counterproductive to continue to resist drug therapy for Parkinson's Disease?



Starting a treatment plan is always a cooperative effort between the specialist and the individual. It is important to be appropriately educated about medications or

therapy before you agree to do them, because if you aren't committed to the plan, it won't work.

Since Parkinson's disease (PD) is a progressive disorder, at some point, the person with PD will need medication to achieve maximum function. Most PD

specialists believe medications should be initiated when:

- The disease has begun to threaten a patient's ability to handle daily activities
- When there is a significant worsening of balance
- When it threatens employability and ability to handle financial or social affairs.<sup>1</sup>

Additionally, we know exercise can make a big difference in managing PD and keeping the patient active. Our goal is to make sure they are able to do those things they enjoy doing and maximize their quality of life. So if PD symptoms are limiting a patient's ability to exercise, medication can help maintain a high level of activity.

# Is there any chance that a medication pump will go into use for PD meds?

Two different medication pumps have been developed for refractory (hard to treat) motor fluctuations in Parkinson's disease, the levodopa/carbidopa



Defining EXCELLENCE

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### WANT TO CONTRIBUTE?

This newsletter is yours, and we think you should be involved. If you have art, poems, or stories you'd like to share with other PD patients, please e-mail them to nwpadrecc@va.gov with "Newsletter submission" as the subject line.

Or mail to: VA Portland HCS P3-PADRECC

3710 SW US Veterans Hospital Road

Portland, OR 97239

# **Registration Now Open for Savvy Caregiver Class**



This is a six-week psycho-educational series sponsored by VA Portland at locations in Portland, Salem, and West Linn. Start dates for classes in these locations begin in January and February (please call for more info).

The series is designed especially for unpaid caregivers caring for a loved one with a dementia diagnosis. Class size is limited and participants must pre-register.

For More Information: Contact Kristi Ketchum at (503) 220-8262 ext. 58594

# (Ask the Experts, continued)

intestinal gel pump (LCIG) and the apomorphine pump. These are already available in Europe, but are under investigation in the US for use here.

The LCIG pump infuses levodopa into the small intestine through gastrostojejunostomy (PEG-J) tube. This is a tube that goes from your small intestine and exits on the surface of your abdomen to allow for infusion from a pump outside the body. Possible side effects of the LCIG include abdominal pain and complications of PEG-J insertion. Interim results from an open-label, international study of the LCIG show significant improvement in motor fluctionations. However, about one-third of patients reported serious adverse events.<sup>2</sup>

The apomorphine pump allows continuous subcutaneous (under the skin) injection of a dopamine agonist. Possible side effects of the apomorphine pump include nausea and skin site reactions. Certain centers are currently enrolling patients in phase 4, efficacy and safety study of the apomorphine pump for improvement of motor symptoms in Parkinson's disease subjects.<sup>3</sup>

### References

- 1. Parkinson Study Group Survey 1989
- 2. Fernandez, H. et al. "Levodopa-carbidopa intestinal gel in advanced Parkinson's disease open-label study: Interim results." Parkinsonism Relat Disord. 2013 March; 19(3): 339-345.
- 3. www.clinicaltrials.gov Identifier. NCT01770145

# WHAT'S NEW IN HOME EDUCATION?

The Southwest PADRECC is sponsoring a monthly support group available by phone! Content will be geared toward Veterans with Parkinson's Diease and family members. Topics will be announced prior to each call.

If you'd like to dial in, the phone number and participation code will remain the same for all dates. Feel free to call a few minutes early to chat with other PADRECC Veterans and Caregivers.

- No pre-registration required!
- These calls are free and open to Veterans and Caregivers
- Feel free to call in early to chat. The conference will start on the hour.
- Please keep background noise to a minimum so everyone can hear

# DATES FOR THE FIRST HALF OF 2015:

January 13th, 2015 | February 10th, 2015 | March 10th, 2015 April 14th, 2015 | May 12th, 2015 | June 9th, 2015

**TIME:** 10:00 a.m. Pacific Time (9:00 a.m. Alaska time, or 11:00 a.m. Mountain Time)

**TO PARTICIPATE, CALL:** 1-800-767-1750, enter code: 54321# For questions, contact the NW PADRECC at (503) 721-1091

# GET MOVING! AROUND THE PACIFIC NORTHWEST

# DANCE FOR PARKINSON'S

Each class uses dance, live music, and community to develop artistry and grace while addressing such PD-specific concerns as balance, flexibility, coordination, gait, and isolation. Whether seated or standing, people with Parkinson's, Caregivers, and friends will enjoy this creative and welcoming environment. No dance experience necessary.

Winter Session Dates

**Des Moines, ID** | 2/23-4/06, Mondays at 2:00pm **Issaquah, WA** | 1/07-2/25, Wednesdays at 10:00am **Seattle, WA** | 1/08-2/26, Thursdays at 11:00am **Kirkland, WA** | 1/10-2/28, Saturdays at 11:00am

Classes are also available in Boise, ID. For addresses, contacts for specific locations, and more information, go to: https://nwpf.org/participate/exercise-movement/dance-for-pd/

# DANCE FOR PARKINSON'S OREGON

Classes integrate movement from multiple dance forms, music of all styles, and theatre vocal games which stimulate and develop the mind, memory, body, and voice.

This class is appropriate for anyone at any stage of the PD condition (students are able to use their wheel chairs of walkers during the entire class if needed), and no partner is necessary.

**East Portland, OR** - Russellville Park 20 SE 103rd Ave | Portland, OR Mondays, January 5th - February 28th

**SW Portland, OR** - Mittleman Jewish Community Ctr 6651 SW Capitol Hwy | Portland, OR Wednesdays, January 5th - February 28th

Contact: Virginia at 503-789-4575 or danceforparkinsonsoregon@gmail.com



# YOGA FOR PARKINSON'S

# Bothell, WA

Northshore Senior Center 10201 E Riverside Drive | Bothell, WA

For information about cost and dates, contact: Melissa at 206-946-6515 or melissa@nwpf.org

# PEDALING FOR PARKINSON'S

# Bellingham, WA

Bellingham YMCA 1256 N State St | Bellingham, WA Mondays, Wednesdays & Fridays Two Classes: 10:00am & 12:00pm

For cost and more information, contact: Tammy Bennett tbennett@whatcomymca.org or 360-733-8630

# Bothell, WA

Northshore Family YMCA 11811 NE 195th Street | Bothell, WA Mondays, Wednesdays & Fridays, 3:15pm - 4:15pm

For cost and more information, contact: Jenny Ferrerira at 425-318-8025 or jferreira@seattleymca.org

# Mill Creek / Everett, WA

Mill Creek Family YMCA 13723 Puget Park Drive | Everett, WA Mondays, Wednesdays & Fridays, 9:00am - 10:00am

For cost and more information, contact: Gael Thomson at 425-357-3033 or gthomson@ymca-snoco.org

# Seattle, WA

Downtown Seattle YMCA 909 4th Ave | Seattle, WA

Mondays, Wednesdays, & Fridays, 10:00am - 11:00am (tandem biking option available)

For cost and more information, contact: Bergen Beck at 206-382-5088 or bbeck@seattleymca.org

# Shoreline, WA

Dale Turner Family YMCA 19290 Aurora Ave N | Shoreline, WA Mondays, Wednesdays & Fridays, 10:45pm - 11:45pm

For cost and more information, contact: Jeanne Kieffer at 206-524-2230 or jmk51@1.com



VA Portland Health Care System P3-PADRECC 3710 SW US Veterans Hospital Rd. Portland, OR 97239

Phone: (503) 721-1091

Seattle VA Puget Sound Health Care System Neurology 127 1660 S. Columbian Way Seattle, WA 98108 Phone: (206) 764-2021 nwpadrecc@va.gov

# CALENDAR OF EVENTS

Upcoming classes, support groups, and other events related to movement disorders

### **PORTLAND PADRECC**

# WHAT'S A DRIVING EVALUATION ABOUT? February 26, 2015,10:00 - 11:30 a.m. Pacific Time VA Portland - Auditorium

Occupational Therapist Frank Pilarski, OTR/L, CDRS will discuss what is involved in receiving a driving evaluation at the VA. Call to register for Portland, or ask about our video-teleconference locations. You can see the presentation via teleconference at various locations in Washington, Oregon, Idaho, and Alaska. Register at (503) 721-1420

## **CHECK OUT OUR WEBSITE:**

## www.parkinsons.va.gov/northwest

Here are some things you can find on the Northwest PADRECC website:

- PADRECC clinic, staff, and contact information
- Information about PD and its treatments
- Information about support groups and other helpful outside resources
- Patient education events
- Patient video library, including "My Parkinson's Story Videos
- Information about how to sign up for "My Health-e Vet"

### **OHSU PARKINSON CENTER**

# CAREGIVER CONNECTION: A NIGHT TO RELAX February 12, 2015, 5:00 - 8:30 p.m. Doernbecher Hospital - Vey Auditorium

The OHSU Parkinson Center and Parkinson's Resources of Oregon are teaming up to offer you an evening of relaxation, connection, and learning. The evening will begin with a relaxing visit over hors d'oeuvres and beverages, and end with a delicious dessert.

Keynote speaker Elaine Sanchez, co-founder of Caregiverhelp.com, author, and presenter will blend humor and practicality in a presentation about the conflicting emotions experienced by Caregivers. Next, Julie Carter, ANP and Jason Malcom, LCSW will present breakout sessions, discussing practical caregiving tips and communication about difficult issues. Register at www.ohsubrain.com/pco.

## PARKINSON'S RESOURCES OF OREGON (PRO)

# COGNITIVE CHANGES IN PARKINSON'S January 30, 2015, Noon - 1:00 p.m. Legacy Salmon Creek Hospital

Presented by Dr. Richard Rosenbaum. Learn how Parkinson's disease can affect thinking and memory, how to identify if this is a problem, and what treatment options and strategies exist to help.

Register at www.pro.eventbrite.com or call 800-426-6806