



In this issue ...

Pg. 1
Become a Member

Pg. 2
From the President

Pg. 3
FDA approves new drug to treat NOH in PD

Pg. 4
Pardon our mess! Upcoming Programs & Events

Pg. 5
Events Recap

Pg. 6 & 7
Moving Day walk

Page 8
Annual Member Meeting Invitation

Become a NPF Heartland Member!
Help Those Affected with Parkinson’s Disease!

This year the National Parkinson Foundation Heartland Chapter (NPF Heartland) provided more than 800 Parkinson’s patients and their care partners with services and resources that are vital in enabling them to improve their quality of life and fight this disabling disease. In the Kansas City metro area, the State of Kansas and Western Missouri, 40,000 people are estimated to have Parkinson’s disease, a chronic, degenerative neurological disorder that affects both voluntary involuntary movement. Another 40,000 or more will be affected as they assume the role of long-term caregiver.

Help us help those affected with Parkinson’s by becoming a member of NPF Heartland! Through your annual membership support, NPF Heartland will be able to provide programs and services such as support groups for those with Parkinson’s and their caregivers, a variety of therapeutic exercise classes, our annual education symposium, and a multitude of resource referrals to people with Parkinson’s disease. Through your support, we will be able to reach more people and expand our services.

Help us continue to aid those affected by Parkinson’s and their families.
Just fill out the form below and mail to the address listed OR go to www.parkinsonheartland.org/join.html to join online.
Help us do whatever it takes to beat Parkinson’s!

I/We want to renew membership OR I/We want to become a new member

Membership Level: \$25 Individual \$50 Family \$100 Professional

Additional Donation: _____

My check payable to “NPF Heartland” is enclosed.

Charge \$ _____ to my Visa AMEX Mastercard Discover

Name on card _____

Account number _____

Expires _____ CCV code _____

Address _____

City _____

State _____ Zip _____ Phone _____

Email _____

By mail: Fill out this form and mail to NPF Heartland, 8900 State Line Road, Suite 320, Leawood KS 66206

By phone: call 913.341.8828 **Online:** www.parkinsonheartland.org/join.html

From the President



In our winter issue, I shared with you the revised mission for NPFH as well as one of NPFH's five values—Community. In this issue, I'd like to focus on another one of our five values:

Dedication

For all of us, whether we are a person with Parkinson's, a caregiver, a family member, volunteer or staff person, this word is part and parcel of what we live every day. Dedication takes on different forms of expression, based on where we enter the picture of Parkinson's disease.

To a person with Parkinson's, it means being dedicated to taking care of your health, coming to exercise classes, staying active, and managing medications.

To care partners, it means not only dedicating time to improve the quality of life for a loved one affected by Parkinson's, but being equally dedicated to taking care of your own needs in order to be a strong and helpful partner in care.

To those in our medical community, it is a dedication to finding a cure through ongoing research, and providing the most up-to-date information, treatments, and therapies for those with Parkinson's.

To community service providers, it means being dedicated to providing the best services possible to match needs that include medical and non-medical home care, living facilities ranging from independent to skilled nursing, self-advocacy, grief counseling, palliative and hospice care.

To board members, volunteers and staff members, it means dedicating time and effort to raise awareness about this disease and the services provided by NPFH, and continuing to expand NPFH in order to serve more people touched by Parkinson's.

When we all come together, dedicated to the same goals and outcomes, great things happen. Thank you all for making great things happen in our community.

Warm Regards,

Nancy Thomsen

2014—2015 Board Members

President

Nancy Thomsen

Vantage Investment Partners, LLC
Financial Planning Advisor

Vice President

William Moler

Tallgrass Energy LP
Sr. Vice President and Chief Operating Office

Vice President

Lawrence (Larry) Bigus

Stinson Morrison Hecker LLP
Retired

Secretary

Graham Smith

Gould Evans Associates
Vice President of Planning

Treasurer

Phil Zaman

CBIZ National Tax Office
Director

Immediate Past President

Kirk Gutekunst

UMB
Senior Vice President, Consumer Services

Jannsen Bruse

Kansas Municipal Energy Agency
Manger, Member Services

Ryan Chance

Ernst & Young, LLP
Senior Manager

Suzanne Dimmel

DTZ
Senior Vice President

Denise Franklin

Franklin Homes of Reece and Nichols
Realtor

Grover Ross Simpson

Colliers International
Associate

Dr. Peter G. Smith

University of Kansas School of Medicine
Professor, Dept. Molecular and Integrative Physiology

Gordon Wood

Endure Energy, LLC
Executive Vice President

FDA Approves New Drug to Treat Neurogenic Orthostatic Hypotension in PD

By Stanley P. Fisher, M.D.

Co-director of Saint Luke's Marion Bloch Neuroscience Institute



After years of clinical research, the FDA recently approved the first drug specifically designed to treat patients with neurogenic orthostatic hypotension (NOH)—most commonly described as a feeling of light-headedness, dizziness, or impending blackout when a patient moves from a sitting to standing position.

Some estimates have shown that as many as 60 percent of patients with Parkinson's Disease will suffer from NOH at some point, which can reduce mobility and quality of life due to constant fatigue and a fear of falling.

Frequency and severity of symptoms can vary greatly from patient to patient. The most pronounced symptoms of NOH are dizziness and lightheadedness that can lead to fainting when moving from a lying or sitting to standing position. This happens because of cerebral hypoperfusion—essentially, the brain is not getting enough blood. Less severe hypoperfusion can cause fatigue, mental fog, headache, and difficulty concentrating. More severe hypoperfusion can cause blurring or loss of color vision, dull aches in the back and neck, and fainting.

For years, movement disorders specialists have treated NOH by using medications to simply raise the patient's blood pressure. There was, however, the potential for negative side effects, including elevated blood pressure while lying flat, and the long-term risks that come with that.

The new drug, called Northera™ (droxidopa), has shown to help increase blood pressure and normalize the body's response to a sudden positional change, reducing or eliminating cerebral hypoperfusion.

It is important to note that while this new medication may provide relief for patients with NOH, a first step would be to consider nonpharmacological steps to reduce symptoms. My patients often see improvements after changing their diet, exercise, and sleeping habits. Try these easy tips:

- Avoid large meals, high glycemic index carbohydrates, caffeine, and alcohol
- Increase salt and fluid intake
- Treat constipation and urinary retention
- Try aerobic and resistance exercise in a safe environment
- Elevate the head of your bed 20-30 degrees
- Make more gradual moves from laying to standing
- Discuss with your doctor a discontinuation of antihypertensive medications, especially beta blockers (except when used for nocturnal hypertension)
- Use high-level compression stockings and abdominal binders

In summary, we have several options for treating NOH, and preventing related disability and injury among PD patients. It is important that you relate your symptoms to your neurologist or cardiologist, who can then assess your particular needs and provide further guidance.

Stanley P. Fisher, M.D., is co-director of Saint Luke's Marion Bloch Neuroscience Institute. Dr. Fisher is one of the nation's leading experts in the field of movement disorders.

NPFH Office Will Be Renovated in July

UNDER CONSTRUCTION

The NPF Heartland offices will be getting a much needed facelift in July. We will be installing new carpet, painting the walls and enlarging the area used for dance and wellness classes.

While construction is underway July 13 – August 20, all of our Dance and Wellness Program classes will be held at Lakeview Village located at 9000 Park Street in Lenexa, KS. Lakeview will also be providing lunches at no charge for Wellness class participants on Tuesday and Thursdays, compliments of their restaurant: Lakeview Bistro and several community partners who have agreed to be lunch sponsors.

- Monday classes will be held from 11:00 – noon (see insert for locations)
- Tuesday and Thursday classes will be held from 10:30—1:00 (see insert for locations)
- Wednesday classes will be held from 10:30—11:30 (see insert for locations)

Our staff will be out of the office during the heavy construction phase (first two weeks) and working remotely. ***If you should need any information during that time, please call our NPF HELPLINE at 1-800-473-4636 and they will assist you or have a local staff person contact you.***

Upcoming Programs & Events



National Parkinson Foundation Heartland Chapter Annual Meeting

Wednesday, August 12, 2015
5:30pm—7:00pm

Colonial Church in Prairie Village
7039 Mission Rd, Prairie Village, KS
See back cover for details!



9th Annual University of Kansas Medical Center's Parkinson's Disease Symposium

Saturday, August 15, 2015
8:00am—1:00pm

Overland Park Marriott
10800 Metcalf, Overland Park, KS
Register by calling 913.588.6921 or
online at <http://www.kumc.edu/parkinson>
(click on upcoming events)



Mid-Missouri Parkinson's Disease Patient and Caregiver Conference

Saturday, July 25, 2015
8:00am-12:30pm

Holiday Inn Executive Center
2200 1-70 Drive SW, Columbia, MO
Register online at
medicine.missouri.edu/parkinsons.
Space is limited.



Community Presentation:

Long-Term Care Insurance,
Stanna Martin, President Mrs. LTC
Wednesday, September 2, 2015
Time and Location to be announced
Visit www.parkinsonhearland.org or
call 913.341.8828 for details

For information regarding support groups, exercise classes and other opportunities, visit our website at www.parkinsonhearland.org



THE 2015 BASKETBALL

The 15th annual BasketBALL event was a Roaring success! With more than 400 attendees, fun was had by all while raising funds to fight Parkinson's Disease.



Thank you to all our volunteers and sponsors who made this event possible and successful!

Caring for the Long Term Caregiver Symposium



Our annual educational symposium was held for the first time ever in Kansas City and focused for the first time on the needs of care partners for individuals with Parkinson's Disease.

Held April 25, 2015 at Johnson County Community College, more than 55 individuals learned about Parkinson's from movement disorder specialist Susan Sifers, MD, MS, a Fellowship-trained Movement Disorders Neurologist at Saint Luke's Neurological Consultants. In addition, they heard and participated in presentations focused on: the grief process as it relates to long-term, chronic illness; self-care for the caregiver, and elder/disability law.

LSVT Big and Loud Therapies were also provided by the staff of Lakeview Village Continuing Care Retirement Community for the individuals with Parkinson's who were in attendance.



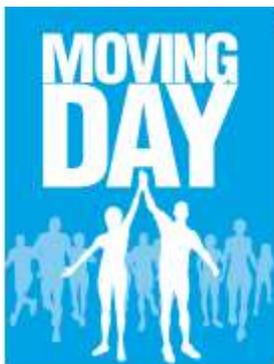
Special Thank You to Our Presenting Sponsor:



Thank You to Our Vendors:



Moving Day® 2015: A Walk for Parkinson's



JUNE 13, 2015
KANSAS CITY



The Moving Day® Walk, a national walk and signature event for Parkinson's, was held on the grounds of Liberty Memorial Saturday, June 13, 2015. Over 600 participants gathered to walk, braving the rain while raising money and awareness for Parkinson's.

Festivities were emceed by Dick Wilson from KSMO 94.9 and the crowd was energized by the JCCC Golden Girls along with the NPFH Exercise Instructors. The National Anthem was sung by Ashtyn Clay and Kama Sanguinetti, from the National Parkinson Foundation, led us in the Moving Day® Parkinson Pledge.

The day was a success because of the teams that participated, our volunteers, community partners and sponsors! We couldn't do this without every one of you!

Moving Day® 2015 brought in more than \$100,000 and money is still coming in! The funds raised support education and outreach in the Heartland, as well as national research. It isn't too late to donate to this important fight against Parkinson's Disease. Go to www.movingdaykansascity.org no later than July 13 to find out how.



Moving Day® 2015 Hall of Fame.

Stew's Crew—Top Fundraising Team



Dancing for Dorothy—Most Team Spirit and Best Dressed Team



Jan's Fans—
Team with the
Most Walkers



Rockhurst Student
Volunteers who ran the
Bernie Boudin Moving
Experience

Thank you to our 2015 Moving Day® Sponsors!



Thank you to our in-kind sponsors:



**National Parkinson
Foundation Heartland**

8900 State Line Road
Suite 320
Leawood KS 66206

913.341.8828 office
www.parkinsonheartland.org

At NPF Heartland, our mission is to improve the quality of life for people touched by Parkinson's Disease through a community approach providing outreach, education and resources.

Executive Director
Jane Ann Gorsky
janeann@parkinsonheartland.org

Events & Development
Liz Goyer
liz@parkinsonheartland.org or
Nancy McGuire
nancy@parkinsonheartland.org

Bookkeeper
Stacey Stark
accounts@parkinsonheartland.org

Office/Marketing Manager
Lori Williams
lori@parkinsonheartland.org

Wellness Coordinator
Kathy Mayer

Wellness Instructor
Janis Rovick

Dance Instructor
Suzanne Ryan

This newsletter is published by NPF Heartland to help people with Parkinson's, their relatives, friends and caregivers. It is not intended to provide personal medical advice, which should be obtained directly from a physician. Please contact us if you have suggestions as to how we can better serve you.



Non-Profit
U.S. Postage
PAID
Shawnee Mission, KS
Permit No. 1268



Follow us on Twitter!
@NPFHeartland

attend our annual
MEMBER MEETING

Calling all NPF Heartland members.....

All current members are invited to the NPF Heartland annual meeting which will include an overview of this year's accomplishments and election of new board members.

Annual Member Meeting
Wednesday, August 12, 2015
5:30pm—7:00pm

Colonial Church in Prairie Village
7039 Mission Rd
Prairie Village, KS 66208

RSVP required by August 3rd to
janeann@parkinsonheartland.org
or 913.341.8828

Find us on Facebook!
www.facebook.com/parkinsonheartland

