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## April is Parkinson's Awareness Month!

Every year, we participate in Parkinson's Awareness Month activities, with a goal to raise public awareness of Parkinson's disease. We do this for many reasons including helping people recognize the symptoms of the disease so that people who may have Pd, and their family members, can seek appropriate diagnosis and treatment. It is also important that the public understand the disease and what a person with Pd might be going through so that they are treated respectfully and appropriately. Awareness month is also a great time to educate decision makers of the need for continued quality research.



We encourage you to create an awareness event. Perhaps you can set up a display at a local library or shopping center kiosk, speak at a civic group meeting, hold a fund-raiser in honor or memory of your loved one, ask your local governing body to proclaim April Parkinson's Awareness Month, or create another activity that will help raise awareness. If you need help, NPF Heartland can provide you with materials and advice.

NPF Heartland is also excited to join communities across America in support of the National Parkinson Foundation (NPF) *Whatever It Takes to Beat Parkinson's* campaign, a national movement to raise awareness of Parkinson's disease to empower people affected by Parkinson's to make positive choices for their health and wellbeing.

"Every person with Parkinson's should know that they can help fight the impact of the disease," stated Joyce Oberdorf, NPF's President and CEO. "No one is too old or too sick to see improvements in their daily life. This campaign brings to light the many ways that anyone can take action, and arms them with the resources they need to live their best life with Parkinson's. It speaks to the core of our mission to improve care, and improve lives."

The centerpiece of the *Whatever It Takes to Beat Parkinson's* campaign is a graphic mosaic of NPF's blue ribbon "P" for Parkinson's, made up of more than 100 unique icons. Each icon represents a means to beat Parkinson's— from yoga, to keeping a balanced diet, to staying positive and seeking out the right treatments. The graphic is being introduced as the national symbol for living well with Parkinson's disease.

You can learn more about the campaign and request flyers, posters and other materials by linking to the interactive webpage at [www.parkinsonheartland.org](http://www.parkinsonheartland.org). NPF Heartland is dedicated to raising the awareness of the disease on many levels, but we need your help.

# From the President



## *Friends & Family,*

I hope this message finds you with aspirations of New Year's resolutions as well as reflective thoughts of those that mean the most to you.

Over the holiday season the Parkinson Foundation's Board of Directors started the New Year by conducting our Board retreat. At this half-day session, we reflected on the NPFH mission and collaborated on plans

to ensure our sub-committee goals are in direct alignment with those. We now plan to take these goals and objectives and put them into action which we will be sharing with you in the coming months. I can tell you that the members of the Board of Directors are truly dedicated to the support of this organization and passionate about its success.

As we begin a new year of activities and festivities, I believe it's important to celebrate and support not only those diagnosed with Parkinson's, but also the caregivers. Too often we overlook or discount the effort that is put forward by our cherished caregivers. The commitment of time, attention, emotional support, patience and dedication of a caregiver is matched by few. It becomes a new way of life for someone that is used to being independent, just like our loved ones with Parkinson's.

On occasion, we may see our caregivers in time of frustration which causes initial feelings of grief. This becomes our time to embrace our caregivers and let them know how much they are appreciated. NPF Heartland has support groups for our caregivers that can provide a forum for knowledge exchange and simply a venue to share experiences.

One of my New Year's resolutions is to reflect more about the caregiver in our family, my mother. I would encourage you to do the same so we are sure to support and celebrate those individuals that are the foundation of success to our mission: "To improve the quality of life for people affected by Parkinson's disease through programs, education, advocacy and research."

*Warm Regards,*  
Kirk Gutekunst

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## Caregiver Recognition

We would like to recognize caregivers on our website's homepage during the month of April for **Parkinson's Awareness Month**. If you know of a caregiver you'd like to recognize, please send their name to [angela@parkinsonheartland.org](mailto:angela@parkinsonheartland.org) or call the office at 913.341.8828.



# THE BASKETBALL 2013

Watch the Final Four Games  
 Play Cards in the Casino  
 Pop-a-shot Competition  
 Great Food & Open Bar  
 Live & Silent Auctions



**Make your reservation online at  
[www.parkinsonheartland.org](http://www.parkinsonheartland.org) or  
 call 913.341.8828.**



Honorary Chair  
**Michael Coleman**  
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**Saturday, April 6**

College Basketball  
 Experience  
 at the Sprint Center

4:30pm - 11pm  
 Casual Attire

**Saturday, June 15**

9:30am

Prairie Village Shops

Moving Day is our signature fund-raising walk. Our event features a unique Movement Pavilion, with stations such as seated exercise, boxing, and the Parkinson's Experience.



**JUNE 15, 2013  
 KANSAS CITY**



Whether you take part on a team or join as an individual, you'll get a chance to move with supporters who share a common goal – to help beat Parkinson's!

Moving Day is FREE to register, although we do hope that you will fundraise on behalf of NPF Heartland.

To register as a team or individual walker, please visit:

[www.movingdaykansascity.org](http://www.movingdaykansascity.org)

## Thanks to our 2013 Corporate Sponsors!

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### 2013 Sponsorship Opportunities Still Available!

contact the office for details or visit  
[www.parkinsonheartland.org/beasponsor.html](http://www.parkinsonheartland.org/beasponsor.html)

# Progression Of Parkinson's Disease Slowed & Symptoms Improved Over At Least A 2-Year Period

*Reprinted with permission from Thomas Jefferson University, December 4, 2012.*

Treating Parkinson's disease patients with the experimental drug GM1 ganglioside improved symptoms and slowed their progression during a two and a half-year trial, Thomas Jefferson University researchers report in a new study published online in the *Journal of the Neurological Sciences*.

Although the precise mechanisms of action of this drug are still unclear, the drug may protect patients' dopamine-producing neurons from dying and at least partially restore their function, thereby increasing levels of dopamine, the key neurochemical missing in the brain of Parkinson's patients.

The research team, led by senior author Jay S. Schneider, Ph.D., Director of the Parkinson's Disease Research Unit and Professor in the Department of Pathology, Anatomy and Cell Biology and the Department of Neurology at Jefferson, found that administration of GM1 ganglioside, a substance naturally enriched in the brain that may be diminished in Parkinson's disease brains, acted as a "neuroprotective" and a "neurorestorative" agent to improve symptoms and over an extended period of time slow the progression of symptoms.

What's more, once the study participants went off the drug, their disease worsened. The study enrolled 77 subjects and followed them over a 120-week period and also followed 17 subjects who received current standard of care treatment for comparison.

"The drugs currently available for Parkinson's disease are designed to treat symptoms and to improve function, but at this time there is no drug that has been shown unequivocally to slow disease progression," said Dr. Schneider. "Our data suggest that GM1 ganglioside has the potential to have symptomatic and disease-modifying effects on Parkinson's disease. If this is substantiated in a larger clinical study, GM1 could provide significant benefit for Parkinson's disease patients."

Symptoms of the Parkinson's disease, which affects over 1 million people in the United States today and is diagnosed in 60,000 adults every year, include tremors, slowness in movement, difficulty initiating movements, difficulty

walking, balance problems and decrease in speech volume and facial expression. The motor symptoms of Parkinson's disease result from the death of dopamine-producing neurons in the substantia nigra, the brain region that dies in Parkinson's disease; the cause of this cell death is unknown.

GM1 ganglioside is a chemical that is normally found in the brain and part of the outer covering of nerve cells. It plays important roles in neuron development and survival and modulates a wide variety of cell activities. GM1 has been found to rescue damaged neurons and increase dopamine levels in pre-clinical studies, and has been suggested to have beneficial effects in other neurodegenerative conditions.

Dr. Schneider and his team made a case for the use of GM1 for Parkinson's disease beginning in the 1980s. The pathological processes contributing to the development and progression of Parkinson's disease are still unclear, but they appear to be multifactorial. Because GM1 has effects on many different cellular functions, it seemed a logical approach to try using a drug like GM1 ganglioside to modify the pathological processes occurring in Parkinson's disease, rather than focusing on a specific potential disease mechanism, said Dr. Schneider.

"Instead of a magic bullet, we think of it like a magic shotgun," he said. "This study was truly a success of translational research."

The GM1 research started in mice, where Dr. Schneider and his team found that animals with an experimentally induced form of Parkinson's disease and administered GM1 had significantly higher levels of dopamine in their brains and less loss of dopamine neurons than animals that did not receive GM1.

A follow-up study in a non-human primate Parkinson model found similar results: animals that received GM1 had higher levels of dopamine than animals that did not and had a significant improvement in Parkinson symptoms.

In the late 1990s, Dr. Schneider conducted a short-term study (16 weeks) using GM1 in a small number of patients. Improvement in symptoms was observed in patients who received GM1 compared to patients who received a non-active placebo. However, in order to determine if there was potential for GM1 to slow the progression of the disease, they would have to study patients over a longer period of time - which led them to this current study.

There were three main groups of subjects in this controlled, randomized, delayed start trial funded by the National Institutes of Health. Patients were given a placebo for the first six months and then GM1 for 2 years (known as the delayed start group); patients were given GM1 from the beginning and continued on GM1 for the duration of

the study (early-start group); and a comparison group, where patients agreed to be observed over the same time period, but did not take the drug or a placebo - they only took the drugs prescribed by their doctor.

The delayed start study design has been suggested to be useful for studying a drug that may have effects both on symptoms and disease progression in Parkinson's disease.

The change over time in the Unified Parkinson's Disease Rating Scale (UPDRS) motor score was the primary measure used to assess symptoms and disease progression in patients.

At the end of the first six months of the study, the early-start group had significant improvement in UPDRS motor scores versus a significant worsening of scores in the delayed-start group. Over the next two years, early start subjects maintained much of the initial benefit of GM1 treatment, showed relatively minor symptom progression compared to patients using standard anti-Parkinson medications, and at the end of the study, their symptoms were still less severe than at the start of the study over two years earlier.

Delayed start subjects also showed improvement of symptoms after switching to GM1 use and also showed less symptom progression over the next two years compared to the standard-of-care patients. Both groups had significant symptom worsening over the next one to two years after stopping use of GM1.

In short, GM1 appeared to improve symptoms and with extended use, slow symptom progression.

"The data from this small proof-of-concept study suggest that GM1 has the potential to have a very positive effect on the lives of Parkinson's disease patients," said Dr. Schneider. "We've been working on this for a long time and have some good ideas on how to move this forward. I think it's important to continue to develop this therapy."

#### References:

Thomas Jefferson University. "Progression Of Parkinson's Disease Slowed And Symptoms Improved Over At Least A 2-Year Period." Medical News Today. MediLexicon, Intl., 3 Dec. 2012. Web 4 Dec. 2012.

## Parkinson's Education Conference Manhattan KS - April 13

Make plans now to attend the always-popular NPF Heartland Parkinson's Education Conference. This year's conference is being held in conjunction with The Parkinson's Program of Manhattan at Meadowlark Hills on **Saturday, April 13, 2013**. The location is in Justin Hall at the Kansas State University in Manhattan, Kansas.

This annual event is aimed at people with Parkinson's, their care partners, family, and health professionals. Attendance is free, but registration is required. Seating is limited. Attendees will receive complimentary food and beverage, materials, and nearby parking.



#### Keynote Presenter

The keynote will be presented by Melissa Kagnoff, M.D., who will share the latest findings on Parkinson's disease and treatment. Dr. Kagnoff completed her fellowship at the Parkinson Disease and Movement Disorders Center at Baylor College of Medicine. The Center conducts 10,000 patient visits per year, and is one of only 27 National Parkinson Foundation Centers of Excellence in the United States.

#### Agenda

9:00am	Doors open, visit exhibits, refreshments
9:30	Welcome and introductions
9:35	Keynote - "PD: What Do We Know Now?" by <i>Melissa Kagnoff, M.D.</i>
10:15	Break and view exhibits
10:30	LSVT LOUD and BIG by <i>National LSVT Faculty</i>
11:30	Lunch/exhibits
11:50	"Home Modifications & Home Safety" by <i>Migette Kaup, Ph.D.</i>
12:30pm	"Crystal Ball - Future of PD" by <i>Melissa Kagnoff, M.D.</i>
1:15	Break-out sessions: People with Parkinson's: Hands-On Consultation by <i>LSVT</i> Caregivers: "Healthy Relationships" by <i>Joyce Baptist, Ph.D.</i>
2:30	Q & A, Evaluation & Adjournment

Registration is easy! By phone, 913.341.8828, or online at: [www.parkinsonheartland.org/symposium.html](http://www.parkinsonheartland.org/symposium.html)

## Save the Date: 2013 Events!

### **Aware in Care Program**

Saturday, March 16  
Overland Park Regional Medical Center

### **Parkinson's Health Fair**

Thursday, March 21  
NPF Heartland Office

### **The BasketBALL**

Saturday, April 6  
College Basketball Experience at the  
Sprint Center

### **LSVT Training & Certification**

Friday, April 12 & Saturday, April 13  
Manhattan, KS

### **Parkinson's Education Conference**

Saturday, April 13  
Manhattan, KS

### **Caregivers' Luncheon**

Thursday, April 18  
Sylvester Powell Community Center - Mission, KS

### **Moving Day: A Walk for Parkinson's**

Saturday, June 15  
Prairie Village Shops

*Questions? Please call 913.341.8828 or email at  
info@parkinsonheartland.org*

## Parkinson's Treatment May Boost Creativity

By Abigail Klein Leichman

*Excerpted and reprinted with permission from the  
Northwest Parkinson's Foundation*

An Israeli neurologist compiled studies on patients who suddenly started drawing, sculpting or writing while on dopamine-stimulating drugs.

Israeli neurologist Dr. Rivka Inzelberg noticed for years that patients taking dopamine-stimulating medication to control symptoms of Parkinson's disease didn't bring her the customary box of chocolates at holiday time. Instead they brought drawings, sculptures or poems they'd created despite never having been artistically inclined before.

"I saw it was becoming such a phenomenon, and I looked

in the literature to see if anyone ever worked on this," she tells ISRAEL21c. "I found many articles about patients who have become artists in the context of being Parkinsonian."

Inzelberg has now written her own article, soon to be published in the journal Behavioral Neuroscience, which reviews and summarizes all the knowledge thus far accumulated about this phenomenon. In the article, she also brings up related questions about the role of dopamine – a brain neurotransmitter that is lacking in people with Parkinson's – on human creativity.

Inzelberg, who treats patients at the Joseph Sagol Neuroscience Center at Sheba Medical Center and teaches at the medical school of Tel Aviv University, says the connection between dopamine and artistic tendencies has been observed for years.

The artist Vincent Van Gogh suffered from schizophrenia, which is characterized by the overproduction of dopamine. And psycho-stimulants such as cocaine and Ecstasy increase activity of dopamine in the brain.

"People think these drugs help them become more creative, but there is no systematic study that checked this, except anecdotal studies among addicts showing creativity or a high self-measure of talent," cautions Inzelberg.

Dopamine's Dark Side.....Too much dopamine may also cause impulsive behaviors, because this brain chemical is responsible for reward-driven behavior and pleasure seeking.

"The feeling of happiness from rewarding activities is transferred by dopamine in the brain," she explains. "It is possible that in patients with Parkinson's, when they take these drugs to ease their muscle disability, a side effect can be a need to do things that bring pleasure in a hyper way such as hobbyism or gambling."

One of the case studies she read involved a medicated Parkinson's patient who painted compulsively around the clock, but stopped when the dosage was reduced.

Inzelberg stresses that not all Parkinson's patients on dopamine-stimulating drugs develop creativity or impulsiveness. She and several colleagues are currently building a battery of tests to measure creative skills and impulse control in order to figure out why some patients on dopamine stimulants develop these traits while others do not.

"This is important for a better understanding of the neurological basis of creativity in 'normal' humans. Is it possible something else aside from dopamine is influencing this?" asks Inzelberg.

"I'm interested in the epidemiology of the disease, what changes its onset and course; genetic factors that influence the course of the disease; and also concomitant diseases."

# Clinical Trials

The following are selected clinical trials related to Pd taking place in our region. For qualifications and more information, contact the person listed with each study.

## Studies for those not receiving treatment

Contact: Kelly Lyons Ph.D. [klyons@kumc.edu](mailto:klyons@kumc.edu) or 913-588-7159

### *Pioglitazone in Early Parkinson's Disease*

Purpose: This is a multi-center, double-blind, placebo controlled clinical trial of two dosages of oral pioglitazone (15 mg and 45 mg) for safety, tolerability, and futility.

### *A Study to Assess Safety and Tolerability of Oral AZD3241 in Patients With Parkinson's Disease*

Purpose: The main objective is to see if safety and tolerability of the drug is acceptable.

### *A Trial of 18F-AV-133 Positron Emission Tomography (PET) Imaging to Differentiate Subjects With Parkinson's Disease (PD) From Other Movement Disorders*

Purpose: The purpose of this study is to determine whether 18F-AV-133 PET scans can be used to differentiate subjects with Parkinson's Disease from other movement disorders.

## Studies for Parkinson's Disease Patients with Off-Time\*

Contact: Kelly Lyons Ph.D. [klyons@kumc.edu](mailto:klyons@kumc.edu) or 913-588-7159

\* Off-Time = time when the medication is not working to its full potential and symptoms are not well controlled. This can be predictable such as wearing off between doses when symptoms return at the end of one dose before the next dose is taken; or this can be unpredictable where medication suddenly loses its effect or when a particular dose of medication does not take effect.

### *A Pilot Study of Oxaloacetate in Subjects With Treated Pd*

Purpose: The purpose of this study is to determine if Oxaloacetate (OAA) is a safe and effective treatment for Parkinson's disease.

### *Extended Release Amantadine Safety and Efficacy Study in Levodopa-Induced Dyskinesia (EASED Study)*

Purpose: To evaluate the tolerability and efficacy of each of three dose levels of ADS-5102 oral capsules, an extended release formulation of amantadine.

## Movement and exercise-related studies:

### *Qigong Exercise*

Purpose: To evaluate Qigong exercise – deep breathing control and meditation, along with mild smooth arm movement – in people with Parkinson's.

Contact: Marshall Schmidt [maschmidt87@gmail.com](mailto:maschmidt87@gmail.com) or Wen Liu [wliu@kumc.edu](mailto:wliu@kumc.edu)

### *Movement and Parkinson's*

Purpose: To study how the brain controls certain types of motion patterns.

Contact: Dr. Gregory King [kinggr@umkc.edu](mailto:kinggr@umkc.edu)

## Additional Resources for Clinical Trials

[www.23andMe.com/pd](http://www.23andMe.com/pd)  
[www.pdtrials.org](http://www.pdtrials.org)  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)  
[www.researchmatch.org](http://www.researchmatch.org)  
[www.foxtrialfinder.michaeljfox.org](http://www.foxtrialfinder.michaeljfox.org)

**3** OUT OF **4** IN THE HOSPITAL...  
PEOPLE WITH PARKINSON'S DON'T GET THEIR MEDICATIONS ON TIME.

## Please Join Us!

Please join us for a FREE program to learn the benefits and use of the "Aware in Care" kit which aims to help people with Parkinson's disease get the best care possible during a hospital stay. Come learn the facts and receive a **FREE Aware in Care kit!**

Aware in Care Program  
Saturday, March 16, 2013  
10:30am - 12:00pm



Overland Park Regional  
Medical Center  
Lower Level Room MPW  
Opening remarks:  
Dr. Muhammed Nashatzadeh

Seating is limited!  
To register call 913.341.8828  
or visit us at  
[www.parkinsonheartland.org](http://www.parkinsonheartland.org)



GET THE KIT. KNOW THE FACTS.  
**BE AWARE IN CARE. >**

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**Gene Hagel**  
Michael & Jill Hagel

**Ann Hecton**  
Mary Louise Dell  
**Joe Jablonski**  
Jodi Karson

**Charlie & Leslie Loftus**  
Larry & Sandy Gutekunst

**Ken & Linda Lutgen**  
Larry & Sandy Gutekunst

**Jim & Donna Morris**  
Larry & Sandy Gutekunst

**Don & Jackie Pellow**  
Larry & Sandy Gutekunst

**Dwight & Charlotte Robinson**  
Larry & Sandy Gutekunst

**Chad Sommer**  
Amanda Buchholz

**Roy Tussey**  
Mary Lee Shucart

**Wedding: Bliss & Nunnink**  
Sarah Becker  
David & Annette Becker  
Douglas & Karen Burton  
Thomas & Lisa Cummings  
Marcia Feighny  
Robert & Paula Harr  
Gerald & Debra Hill  
David & Carol Howell  
John & Marcia Lichtenauer  
Joe & Shirley Lichtenauer  
James Lichtenauer  
Larry & Rita Miller  
Jon & Mary Owens  
James & Renee Sangster

**Wedding: Ernst & Sturdivan**  
Michael & Melia Sturdivan

Pat Adair  
Karen Anderson  
Lorraine Anderson  
Ellen Baker  
George & Sara Baldwin  
Tom Balnis  
Lawrence & Ruth Anne Bigus  
Karlton & Ann Bohrn  
David & Ellen Boles  
Norman Bressler  
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John & Katie Chalfant  
Michael Clark  
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Megan Nicolas  
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Bill & Margie Stroud  
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John & Toni Thornton  
Jacqueline Wood  
Stephen Young

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Donald Boysen  
Marjorie Brammell  
Donna S. Childs  
Jerry & Dorothy Clausen  
Jim & Lou Eisenbrandt  
Dean & Maryem Floyd  
Gloria Freese  
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Kim Glover  
Harry & Katherine Grannemann  
Tom Grimaldi  
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Janice Kinney  
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Larry & Beverly Mallin  
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*Every attempt has been made to reflect accurately and completely the names of our generous contributors. We apologize for any errors or omissions.*



# NPF's Parkinson's Outcomes Project

*The National Parkinson Foundation (NPF) recently released early findings from the largest clinical study of Parkinson's ever conducted, showing that depression is the most important factor influencing the quality of life and health of Parkinson's patients. The study, known as the Quality Improvement Initiative (QII) is collecting data from more than 5,000 people with Parkinson's in four countries. QII is one part of the NPF's broader Parkinson's Outcomes Project to determine what works best in treatment and care with an aim toward slowing the impact of the disease.*

Long used in technology, engineering, and manufacturing, measurement is the foundation for quality improvement in many consumer and industrial products—from cars to computers. In a similar way, by identifying and measuring the underlying factors and treatment responses in Parkinson's patients over the entire course of the disease we can find out what works best.

That's why, in 2009, NPF launched the first data-driven study of outcomes in Parkinson's disease: the Parkinson's Outcomes Project. This initiative, developed in partnership with NPF's Centers of Excellence network, introduces the concept of continuous improvement to Parkinson's care. The goal is to explore the differences in current clinical practice in order to create and spread models of excellent care for best health outcomes. This is key to NPF's mission of making sure that every patient receives the best care possible, whether they are seen by a specialist at an NPF Center of Excellence, a general neurologist, or their primary care physician.

The Parkinson's Outcomes Project tracks and monitors the care over time of patients who are seen at participating NPF Centers of Excellence. Because no two people experience Parkinson's in exactly the same way, the data collected encompasses not only physician assessments, but also patient experience. Putting specialists, surgeons and researchers in communication with one another to share information in this way allows our affiliated centers to pool collective expertise and brain power to move Parkinson's care forward more rapidly.

In addition to medical management, they are exploring other factors that impact the disease. For example, recent studies have consistently found that exercise and physical therapy help improve motor symptoms. It's also been shown that speech therapy helps prevent pneumonia, and occupational therapy helps people live independently and avoid dangerous falls. That's why they are now capturing all of this data as well as referrals to allied health professionals. For the first time, this information will allow us to understand the role that comprehensive care plays in managing Parkinson's disease as well as to establish proven baselines for Parkinson's care that will help guide future research.

Since 2009, more than 6,000 men and women, ranging in age from 25 to 95, have joined the Parkinson's Outcomes Project's research study, representing more than 10,000 clinic visits. They include the largest group of people with young-onset Parkinson's ever assembled (400 people with onset before 40) and the first to study a large group of people (more than 350) who have lived with Parkinson's for more than 20 years. In 2013, NPF will continue to expand the study at Centers of Excellence across the United States and internationally.

## Key Findings:

Negative mood and depression have the greatest impact on health status. At least 40 percent of people with Parkinson's will experience some form of depression, and as many will experience an anxiety disorder. A clear finding from our study is that, taken together, mood, depression and anxiety, have the greatest effect on quality of life, even more than the motor impairments commonly associated with the disease. Further, our analysis found that QII participants who receive care from clinics with the most active approach to psychological counseling report the lowest rates of depression.

Impaired mobility is the second most influential factor on health status. Mobility problems often result in difficulty walking, balance problems and an inability to perform everyday tasks such as feeding and bathing. However, regular exercise — more than 2.5 hours per week — is associated with lower degrees of mobility impairment, caregiver burden and impairment in everyday activities. Our analysis found that people who addressed mood and mobility together — using a full complement of therapies including medicine, surgery and exercise — were the most successful in managing their mobility problems and improving quality of life.

Patients at some centers fare better than similar patients at other centers. Our analysis found that NPF-designated centers differed in patient-reported health status for their patients, with the average health status varying by as much as 13 points after adjusting for disease severity. It is not clear why this is, but we suspect it may be due to a combination of two things: doctors at some centers are getting referred patients who are simply doing worse to begin with, and the centers with the best health outcomes are providing a superior level of care that leads to better results.

Medication use varies substantially from one neurologist to another. Neurologists rely on their best judgment in managing drug regimens, because in many cases there is little evidence to support one choice of medication over another. Our analysis found that some neurologists opt for more complex and individualized medication strategies, while others prescribe simple treatment plans of one or two medications.

Centers refer patients to allied health professionals differently. Referral rates to physical, occupational, speech and other therapists vary by as much as 50 percent for similar patients. For example, we have found that depression seems to be treated most effectively when patients are referred to a counselor, yet not all centers follow this approach.

You can download the full report from our website at: [www.parkinsonheartland.org/medicalnews.html](http://www.parkinsonheartland.org/medicalnews.html)



**We had a blast at Hamburger Mary's!**

Many thanks to everyone who played Ham-bingo with us at Hamburger Mary's KC on December 13th. We raised over \$900 in two hours! Our next Hamburger Mary's date will be sometime in July - watch our website & e-blasts for details.

# Support & Exercise Groups

Below are support groups for people with Parkinson's disease and/or their caregivers. All groups listed are open to the public. Please call the contact listed to confirm days, times and location prior to attending. If you know of any other groups that are open to the public, please let us know by calling 913.341.8828.

## Metro Kansas City – Support Groups

Leawood, KS - Caregivers  
Parkinson Foundation Heartland  
8900 State Line Rd., #320  
2nd Thursday, 10:30am  
Sydney Headrick.....913.341.8828

Leawood, KS – Young Onset  
Parkinson Foundation Heartland  
Call for location – varies  
2nd Saturday, 2pm  
Sydney Headrick.....913.341.8828

Lee's Summit, MO  
John Knox Places Restaurant  
1001 Chipman Rd.  
4th Wednesday, 10am  
Dr. Kelly Lyons.....913.588.7159

North Kansas City, MO  
St. Luke's Presbyterian Church  
4301 NE Vivion Rd.  
4th Tuesday, 1pm  
Alicia Scott.....816.214.7034

Olathe, KS  
College Church of the Nazarene  
2020 E. Sheridan  
1st Wednesday, 6pm  
Dave Smith.....913.888.2091

Overland Park, KS  
Brookdale Place  
6101 W. 119th Street  
2nd Monday, 3pm  
Leslie Fuller.....913.345.9339

Overland Park, KS  
Freedom Pointe  
9201 Foster  
3rd Thursday, 2:30pm  
Tahesha Yearby.....913.385.2052

## Metro Kansas City – Support Groups (con't)

Prairie Village, KS  
Brighton Gardens  
7105 Mission Rd.  
3rd Monday, 1pm  
Sydney Headrick.....913.341.8828

Prairie Village, KS  
Claridge Court  
8101 Mission Rd.  
2nd Tuesday, 7pm  
Catherine Solie.....913.385.4145

## Missouri Support Groups

Branson, MO  
Skaggs Community Health Cntr.  
251 Skaggs Rd.  
2nd Thursday, 2pm  
Charlene Stade.....417.883.0637

Columbia, MO  
Lenoir Community Center  
1 Hourigan Dr.  
1st Thursday, 4pm  
Patsy & David Dalton....573.434.4569

Joplin, MO  
Call for location and days  
Nancy Dunaway.....417.659.6544 or  
417.623.5560

Lake Ozark, MO  
Lake Ozark Christian Church  
1560 Bagnell Blvd.  
3rd Thursday, 12pm  
Patsy & David Dalton....573.434.4569

Lebanon, MO  
Lebanon-Laclede County Library  
913 S. Jefferson  
2nd Wednesday, 2:30pm  
Janice McCauley.....417.269.3616

## Missouri Support Groups (con't)

Monett, MO  
First United Church  
1600 N. Central  
2nd Thursday, 2:30pm  
Judee Steward.....417.269.3616

Springfield, MO  
St. John's Hospital  
2nd Thursday, 2 pm  
Pat Auston.....417.820.3157

Springfield, MO  
Meyer Fitness Center  
1000 E. Walnut Lawn  
Last Wednesday, 3pm  
Judee Steward.....417.269.3616

Springfield, MO – Young Onset  
Meyer Fitness Center  
1000 E. Walnut Lawn  
4th Thursday, 7pm  
Janice McCauley.....417.269.3616

Trenton, MO  
Senior Center  
2901 Hoover Rd.  
1st Thursday, 10:30am  
Gloria Koon.....660.485.6558

## Kansas Support Groups Outside KC Metro Area

Abilene, KS  
Abilene Physical Therapy & Sports  
Rehab  
103 NW 15th Street  
3rd Thursday, 6pm  
Tonya Mills.....785.263.3646

Buhler, KS  
Sunshine Meadows  
Retirement Center  
400 S. Buhler Rd.  
2nd Tuesday, 10am  
LeNora Derkson.....620.543.2251

# Support & Exercise Groups

## Kansas Support Groups Outside KC Metro Area (con't)

Chanute, KS  
Neosho Memorial Regional MC  
629 S. Plummer Ave.  
2nd Thursday, 2pm  
Nancy Brock.....620.537.7386

Emporia, KS  
Presbyterian Manor  
2300 Industrial Rd.  
3rd Wednesday, 1:30pm  
June Hubert....620.412.6458

Great Bend, KS  
St. Rose Ambulatory Center  
3515 Broadway  
Call for date/time  
Mike Mingenback...620.786.6136

Hays, KS  
Call for info  
Eileen Rohrberg.....785.628-1231

Hutchinson, KS  
Hutchinson Public Library  
1306 E. 21st. Street  
2nd Thursday, 10am  
Gary Hughes.....620.663.8780

Junction City, KS /Geary County  
Sterling House  
1022 Caroline Avenue  
1st Thursday, 6pm  
Joye Gfeller.....785.762.3123

Lawrence, KS  
First Presbyterian Church  
2415 Clinton Parkway  
3rd Tuesday, 2pm  
Mary Jane Clement 785.865.2450

Manhattan, KS  
Meadowlark Hills  
2121 Meadowlark Hill  
1st Thursday, 2pm  
3rd Monday, 1pm: Caregivers  
Michelle Haub.....785.537.4610

Marysville, KS  
Helvering Center  
111 S. 8th Street  
2nd Monday, 1:30pm  
Marci Deunsing.....785.562.3224

## Kansas Support Groups Outside KC Metro Area (con't)

McPherson, KS  
Prairie View  
1102 Hospital Drive  
2nd Tuesday, 2pm  
Janell Clary.....620.245.5000

Topeka, KS  
Midland Hospice Church  
200 Frazier Circle  
1st Thursday, 5:30pm  
Rob Peppers.....785.273.9861

Wichita, KS  
Via Christi on St. Francis  
929 N. St. Francis  
3rd Wednesday, 2pm  
Carolyn Cowart.....316.268.8204

Wichita, KS  
Wesley Rehabilitation Hospital  
8338 W. 13th St.  
4th Tuesday, 11:30am  
Dorothy Rousch/Debra Wetta  
316.729.1140

## Kansas Pd Exercise Classes

Manhattan, KS  
Meadowlark Hills  
2121 Meadowlark Hill  
M & F, 1pm  
Michelle Haub.....785.537.4610

## Metro Kansas City Pd Exercise Classes

Kansas City, KS  
Trinity Methodist Church  
5010 Parallel Parkway  
Mondays, 11am  
Emma Jean Claiborn....913.287.3171

Kansas City, MO  
Garden Village  
8550 Granby  
T, Th, Sat 9:30 – 10:30am  
Mary Jane Branch..816.436.5555

## Metro Kansas City Pd Exercise Classes (con't)

Kansas City, MO  
Gardens at Barry Road  
8300 NW Barry Rd.  
M & W, 11am – Noon:  
Stay Strong/Stay Fit  
Anita Yost.....816.741.7725

Kansas City, MO  
Kingswood Senior Living  
10000 Wornall Rd.  
T & Th, 1:30 – 2:30pm:  
Balance & Coordination  
M, W, F, 1:30pm:  
Arthritis Exercise  
M, W, F, 9am and M-F, 1:30pm:  
Aquatic Classes  
All classes free to people with Pd.  
Ray Gilliland.....816.942.0994

Leawood, KS  
Parkinson Foundation Heartland  
8900 State Line Rd., #320  
Tuesday, Wednesday, Thursday  
10:30-11:30am: Seated Exercise  
11:30- Noon: Lunch  
Noon-1pm: Games/Social  
Sydney Headrick....913.341.8828

Shawnee, KS  
Boxing Class \$5/class  
GRITT Fitness  
23704 W. 83rd Street  
Monday, 5:30-6:30pm  
Josh Biles.....913.575.7497



Get your **FREE Parkinson's Disease Alert Bracelet** by calling the NPF Heartland Office at 913.341.8828 or [info@parkinsonheartland.org](mailto:info@parkinsonheartland.org)

**National Parkinson  
Foundation Heartland**

8900 State Line Road  
Suite 320  
Leawood KS 66206

913.341.8828 office  
913.341.8885 fax  
www.parkinsonheartland.org

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Our 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.



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# WALL OF HONOR

We would like to honor those living with Parkinson's disease, caregivers of Pd patients, and those who are no longer with us. For your donation of \$100, we will honor your chosen one with a photo plaque as part of our "Wall of Honor" at the BasketBALL. After the event, the photos will be displayed at the National Parkinson Foundation Heartland office as a tribute to those we serve.

**Here's how you can honor a friend or loved one...**

**On line:** Order your tribute online at [www.parkinsonheartland.org/memorials.html](http://www.parkinsonheartland.org/memorials.html) or email: [angela@parkinsonheartland.org](mailto:angela@parkinsonheartland.org)

**By mail:** Fill out this form and mail to the Parkinson Foundation office along with a photo of your friend or loved one (all photos will be returned) and your check or credit card information.

### Information for the photo plaque:

Honoree \_\_\_\_\_

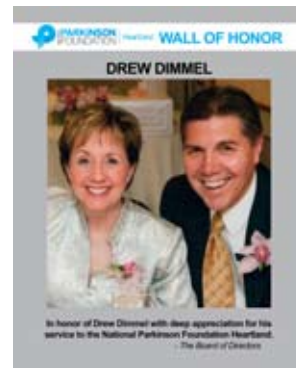
**Category:**

- In memory of...
- Person with Parkinson's disease
- Caregiver

Message (approximately 30 words or less): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Submitted by: \_\_\_\_\_

*Your donation is tax deductible to the full extent permitted by law.*



I/We want to add \_\_\_\_ person(s) to the Wall of Honor for a donation of \$100 per honoree.

- My check payable to 'NPF Heartland' is enclosed
- Charge \$\_\_\_\_\_ to my  
Visa Mastercard Discover AMEX

Name on Card \_\_\_\_\_

Account Number \_\_\_\_\_

Expires \_\_\_\_\_ CCV code \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_