



# PARKINSON UPDATE

Serving Kansas, Missouri and Oklahoma

## Partnerships

❄️ Winter 2008

This issue of the Parkinson Update is dedicated to partnerships. An organization like ours is founded on the idea that we can accomplish things together that we can only dream of alone. We band together and are able to provide critical support services and fund important research projects. Our lives are more complete because of our relationships with one another. All of us at the Parkinson Foundation are grateful for the opportunities we have to know you and to serve you.

I would like to share a small excerpt of an essay written by one of our members, Larry Rutter.

*Most of us have been given many more blessings than we have received. We do not take time to be blessed or make the space for it. We may have filled our lives so full of other things that we have no room to receive our blessings. People with serious illnesses have often let go of a great deal; their illness has created an opening in their lives for the first time. They may discover ways to receive all the blessings they are given, even those that were given long ago.*

*There is in life a suffering so unspeakable, a vulnerability so extreme that it goes far beyond words, beyond explanation, and even beyond healing. In the face of such suffering all we can do is bear witness so that no one need suffer alone. Perhaps a willingness to face such shared vulnerability gives us the capacity to repair the world. Those who find the courage to share a common humanity may find they can bless anyone, anywhere.*

Reading this essay prompted us to explore some of the positives that might come from learning to live with a chronic illness. In this issue, you will find an informative study on the many positive thoughts and

feelings that caregivers discover. There are tips on making changes and regaining control over your life. You will read about our partnerships with the University of Kansas School of Medicine, the Oklahoma Medical Research Foundation and the University of Oklahoma.



*Breakthroughs in Parkinson's disease research are being made every day. See "New Research" on page 6 for more information.*

You will also read about some of the many thrilling breakthroughs being made in Parkinson's disease research, every one of them the result of partnerships between the public and private sector, and between clinicians and researchers and people with Parkinson's disease. As always, full reprints of the excerpted research studies are available in our office; just call and we'll send you a copy. We also have the complete text of Larry's essay.

We send this *Update* to you with our wishes for a happy and healthy 2008, and our hopes that blessings will be uncovered for you!

**PARKINSON FOUNDATION OF THE HEARTLAND**

# From The President



**Mike Dreiling**  
President

Dear Members and Friends,

As the President of the Parkinson Foundation of the Heartland Board of Directors, I would like to take this opportunity to offer my wishes to you for a healthy and happy 2008. This is also a perfect opportunity for us to take stock of our achievements during 2007 and set course for a more successful 2008.

We the Board of Directors believe our driving motivations are two fold. First, to provide support and assistance to those persons afflicted with Parkinson's Disease as well as their families and loved ones. We believe we accomplish this goal through the work our tireless staff and supporters provide throughout the community and at our wellness center. Personally, I can tell you the smiles I see on the faces of our members who utilize our Wellness Center are reward enough for me for devoting my time, energy and financial support to PFH.

Of course, there is a larger purpose in our efforts. Supporting research for new and better therapies, and for the cure, is a critical component of our mission. We are lucky to have in Kansas City a partner in fighting for a cure to Parkinson's Disease in the University of Kansas Medical Center.

Because of your continued support of PFH, we were able to make substantial grants to the University of Kansas to further fund the fight against Parkinson's Disease. First, we gave a grant in the amount of \$25,000 to the University of Kansas to fund a research lab for Dr. Russell Swerdlow, M.D. Ph.D. Dr. Swerdlow, a bench researcher at KUMC, has been involved in pioneering a technique to develop blood platelet hybrids to look at the consequences of mitochondrial dysfunction in PD. Our grant will allow Dr. Swerdlow to develop these cells in his lab at KUMC and these cells would be available for future research internationally. To date, Dr. Swerdlow has already identified a drug that will induce mitochondrial proliferation and intends to study how this drug will affect mitochondria in PD patients.

Secondly, we pledged a minimum of \$25,000 to Dr. Jules Nazarro, M.D., a neurosurgeon at KUMC, in order to help fund a neurosurgical fellow at KUMC. Third, we gave a grant in the amount of \$10,000 to Dr. Raj Pahwa, M.D. and Dr. Kelly Lyons, Ph.D., to be used at their discretion to further their vital work in the research and treatment of PD patients.

We feel very lucky to have such skilled individuals in the Kansas City area as Dr. Swerdlow, Dr. Nazarro, Dr. Pahwa and Dr. Lyons as well as a cutting edge research hospital as the University of Kansas Medical Center. It is our pleasure to work along side these doctors and KUMC in maintaining Kansas City as a Center of Excellence.

In addition, through your efforts and support, we were able to give grants in the amount of \$10,000 each to fund a neurology fellow at the University of Oklahoma as well as to the Oklahoma Medical Research Foundation to fund a bench study project on brain function in parkinsonian rodents.

This is what we were able to accomplish in 2007. This was one of our most successful years since the foundation was created. I can assure you we have no desire to rest on our laurels. We are committed to continuing our success into 2008 and beyond and we will not rest until a cure for Parkinson's Disease is found. With your continued commitment and support of our mission, together we can take Steps To The Cure.

*Mike*

Mike Dreiling  
President

# New Study on Family Caregivers

A new study for the National Alliance for Caregiving and Evercare finds that half of those who care for a loved one 50 years or older are spending more than 10% of their annual income on caregiving expenses and often sacrifice their own long-term financial and personal well-being to do so. The *Evercare/NAC Study of Caregivers – What They Spend, What They Sacrifice* finds that family caregivers, who have an annual median income of \$43,026, spend an average of \$5,531 a year on caregiving, an amount that is \$400 more than the average American household spends each year on health care and entertainment combined, according to the Bureau of Labor Statistics. Further, the study found that at lower income levels the annual average cost remained about \$5,000 – making their financial burden even heavier.

The study also found that one in three participants (34%) had used some of their savings to cover the cost of caregiving and one-quarter (23%) said they cut back on their own health care spending. But, according to the respondents, the most significant sacrifice was their own time spent caring for an older loved one. Importantly, most of the caregivers from the study still saw their caregiving role as a labor of love and one they do willingly.

“Caregivers play a vital – and under-recognized – role in ensuring the health and well-being of our aging population, but in doing so they are neglecting their own futures,” says John Mach, M.D., a geriatrician and CEO of Evercare. “We need to put in place support systems and plans now to help ensure today’s caregivers can be properly cared for tomorrow – and that our society and our health care system are ready to meet their needs.”

The study found the most common caregiving expenses respondents cited were:

- Household goods, food and meals (42%)
- Travel and transportation costs (40%)
- Medical co-pays and pharmaceuticals (31%)
- Medical equipment and supplies (22 %)
- Clothing (21 %)

The study also looked at the difference in costs for varying caregiving situations. Long-distance caregivers

had the highest annual expenses (\$8,728), followed by co-resident caregivers (\$5,885) and those who cared for someone living less than an hour away (\$4,570).

Providing a qualitative look at caregiver costs, researchers asked 41 respondents to keep a detailed diary of their expenses for 30 days. The diarists spent an average of \$1,209 on caregiving over the one-month period.

Extrapolating this cost over a year shows that the diarists were spending twice the average of the other respondents – \$12,348 annually. The study did not assess whether the diarists had more complex caregiving situations than average or whether the telephonic survey respondents underestimated their costs.

More than half of the study respondents (53%) did not work while 37% of the respondents said they had quit their job or reduced their work hours. The respondents also reported they were spending on average 35.4 hours a week caring for their loved one with 19% providing care for more than three years and 32% caregiving for more than five years.

To accommodate the caregiving time and expenses they had, study participants were making the following sacrifices:

- Cutting back on leisure activities (49%) and vacations (47%)
- Saving less or not at all for their children’s future (38%)
- Using their savings (34%)
- Cutting back on basics such as clothing, utilities or transportation (27%) or groceries (24%)
- Cutting back on personal medical or dental expenses (23%)

“Time is the most expensive commodity I provide – but it has no price tag,” one caregiver among the diarists commented. Despite the sacrifice, caregivers also said it was a commitment they made willingly.

While the survey focused on the personal financial costs of caregiving, it also revealed a ripple effect: respondents felt their out-of-pocket costs carried an

*“Time is the most expensive commodity I provide – but it has no price tag...”*

one caregiver’s comments

*Continued on page 4, see “Caregiver Study”*

# What Caregivers Say

The following excerpts are from a 2007 Caring Today/CVS Pharmacy study of 514 adult caregivers.

## Biggest Initial Reactions

When you first realized you were a caregiver, in addition to concern for the person, you remember feeling:

- 43% Overwhelmed
- 34% Fear
- 31% Inadequate

However, after becoming a caregiver, fewer of you felt overwhelmed than anticipated. Even if you said you felt unprepared, you told us that the actual experience turned out to be better than expected.

## Where You First Turned for Help

- 58% Family
- 45% Doctors
- 38% Internet
- 28% Friends

## Primary Concern: Medications

The vast majority – 87% - feels that understanding medications is very important. But you also expressed these major concerns:

- 26% Don't know how drugs interact
- 21% Are not able to recognize side effects
- 17% Don't know what questions to ask

## Where You Get Medication Information:

- 69% Talk to doctors
- 55% Research on the Internet
- 50% Read product information
- 46% Talk with the pharmacist

However, even though you said doctors are the biggest help in easing concerns about medications...42% said you'd like more time with the doctor.

## Expectations vs. Experience

- 46% thought they'd enjoy tasks associated with caregiving, but 69% found that they actually enjoy them
- 60% expected to find caregiving rewarding, but 79% really did find the experience rewarding

## Immediate Needs

What was your most immediate need once you assumed the role of caregiver?

- 37% Establishing life balance among caregiving, family, career and personal needs
- 20% Knowing what to do next
- 19% Needing to understand medical information

## Lifestyle and Health

Since becoming a caregiver, what feelings or actions have increased?

- 59% Quality of relationship with the person I care for
- 41% Being organized
- 33% Feeling focused

However, four in 10 caregivers also report increased feelings of depression and three in 10 think that their health condition has deteriorated since becoming a caregiver.

## Caregiver Study, continued from page 3

emotional and physical price. Study respondents reported on the personal and emotional impact which includes:

- Heightened stress or anxiety (65%)
- Difficulty sleeping (49%)
- Increased financial worries (43%)
- Depression or hopelessness (37%)
- New or worsening health problems (26%)

The care provided by family caregivers is an integral

part of America's health care system. Yet, alarmingly, statistics show that caregivers are twice as likely as the general population to develop multiple chronic illnesses. People with chronic illnesses also are among the heaviest users of medical care in the nation; people with five or more chronic conditions make up just 20% of American age 65 or older, but account for 68% of all Medicare spending.

# Making Changes

Living well with Parkinson's disease depends in part on developing healthy behaviors. For most of us, that requires change. Change just doesn't happen because you want it to; it requires planning, support and persistence.

You and your partner are responsible for managing your condition day to day, and in doing so you face three difficult sets of changes:

- Health condition - including diet, exercise, medications and treatments, and record keeping.
- Functions and roles in life – being able to do the things you need and want to do, and maintaining the best possible relationships with others.
- Emotional demands – dealing with the difficult emotions that come with PD like grief, fear, frustration and anger.

Psychologists who study behavior change have found that, for people to change, they need positive reasons or goals. Since change takes effort, people need motivation. They need rewards that are important to them. One might wonder, isn't a longer, healthier life enough of a reward to motivate people? Often not, as that's a very long term goal, and not guaranteed for anyone. The motivational power of a longer life depends on how rewarding life is now. People need goals that will improve the quality of their lives today or in the near future.

The most effective goals are medium term. This means thinking about a goal that you can achieve in about 3 to 6 months, although you can stretch those limits. Goals can be about physical fitness, like walking a certain distance, or they could be about your life, like being able to continue or develop a hobby.

You will need to ask yourself some questions when setting a goal. Think about things like:

- Is there something I would like to do that my condition currently prevents me from doing?
- Is there an accommodation available to allow me to pursue this goal?
- What would make me excited about getting out of bed in the morning?
- What does my body seem to want from me now?

It's okay, in fact desirable, to ask for help from loved ones, family or professionals when developing your goals.

Goals are generally too big to work on all at once. Break them down into smaller, more doable steps. These smaller steps are "action steps" and can be recorded onto action plans. Post your action plan where it will remind you of your goals and motivate you to continue.

Action plans don't always work well right away. Usually people encounter some barriers they didn't expect when they made their plans. It's helpful to have someone to help with problem-solving, but there are some basic steps you can use on your own. Kate Lorig, a nurse and researcher, has developed a very successful program called the Chronic Disease Self-Management Program for patients. The following steps are adapted from this program:

## Identify the problem.

This may be the hardest part! Writing it down may help clarify your thinking about it.

## Make a list of things that might work to overcome the problem.

You might get help from friends, healthcare professionals, or sources like the Internet or library.

## Select one of the ideas and give it a try for a couple of weeks.

## Assess the results.

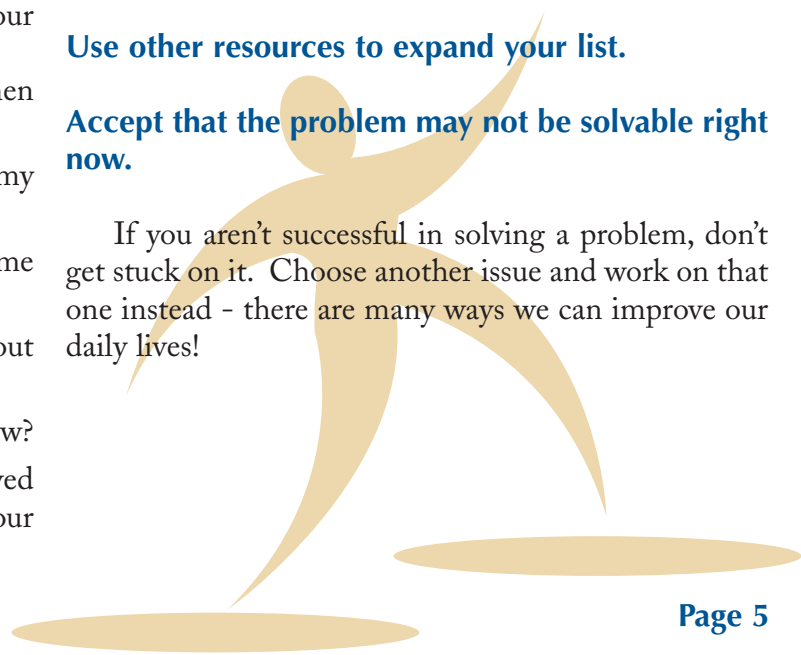
If the problem is solved, great! If not...

## Substitute another idea and see how that works.

## Use other resources to expand your list.

## Accept that the problem may not be solvable right now.

If you aren't successful in solving a problem, don't get stuck on it. Choose another issue and work on that one instead - there are many ways we can improve our daily lives!



# New in Parkinson Research

## Parkinson's Hope

*Proceedings of the National Academy of Sciences, November, 2007*

Brain scans of patients who received an experimental gene therapy for Parkinson's disease provide proof that the therapy actually changes brain circuits. The first person to get the treatments wants to give hope to others who suffer from the disease by sharing his story.

"I couldn't live the way I was living. It was just too intense," says Nathan Klein. The married freelance television producer and father of two was 45 years old when he found out that his tremors and loss of motor control were symptoms of Parkinson's disease. He tried various treatments and medications, including dopamine drugs. Explains Klein, "The symptoms don't get better. They get worse. And the pills you take eventually don't help out. So, you know, what's there to look forward to? Nothing." So Klein researched experimental therapies and four years ago decided to enroll in a clinical trial to assess the safety of an experimental gene therapy for Parkinson's. He became the first person in the world to undergo the procedure. Neurosurgeon Michael Kaplitt of Weill Cornell Medical Center operated on Klein. He injected viruses carrying the therapeutic genes directly into the overactive area of his brain, the subthalamic nucleus, that controls movement. Because of the experimental nature of the study, the twelve participants were only treated on one side of the brain. The study was a joint endeavor with the Feinstein Institute for Medical Research in Long Island.

The patients reported an improvement in symptoms and none

of them had side effects from the procedure. In addition, Feinstein Institute neurologist David Eidelberg and his team performed positron emission tomography (PET) scans on the patients' brains before the surgery, and then again six and 12 months afterward. Eidelberg and colleagues pioneered the use of this technology to identify networks in the brain. In this study, he monitored two different networks, or circuits. One regulates movement and the other is a thinking network. The scans measure activity or metabolism in these networks. "This is the first time that measuring a network has been used to assess the outcome of a trial where you're looking to determine whether a therapy has worked or not," explains Eidelberg.

"The gene therapy study was to look at an area of the brain called the subthalamic nucleus. The area is overactive when you have Parkinson's disease. So it represents a sort of a brake – a braking mechanism in a car. In normal people, when you want to stop moving it's depressed, and when you want to move, the brake is relaxed a bit," says Eidelberg. "Parkinson's – that's pedal to the metal; that brake is pushed all the way down and the person can't move altogether." The goal of the gene therapy is to relax that braking mechanism. "Relaxing it just a tad, just a small degree, can help a person immensely in terms of their capacity to initiate movement, plan movements and do simple day-to-day activities," says Eidelberg.

"My life is a lot better now," says Klein. "I mean an incredible, incredible transformation."

The brain scan study confirms what Klein is feeling. Eidelberg explains that the scans prove the overactive movement network actu-

ally changed. He wrote in the Proceedings of the National Academy of Sciences that treatment relaxed brain activity in the motor network, making a patient with severe over-activity look like a person with moderate or mild Parkinson's disease. And because patients only received the therapy on one side of their brains, the researchers used the untreated side as a control. "The network activity in the treated side went down while the other network in fact got worse over the period of time. It was as if the disease had progressed on one side of the brain, but not the other," says Eidelberg.

Eidelberg and his colleagues plan to start their next clinical trial in early 2008. This will be a double-blind sham-operated placebo-controlled phase II gene therapy study. If the therapy proves beneficial, the group that received the placebo will be offered the therapy after the study ends.

## Autophagy and Parkinson's Disease

*Journal of Clinical Investigation, January, 2008*

A glitch in the way cells clear damaged proteins could be the trigger for the symptoms of Parkinson's disease, researchers said in a finding that could lead to new treatments for the incurable condition. The U.S. team focused on a process called autophagy in which cells digest and recycle damaged molecules, including proteins, that develop as cells grow older. This system essentially renews cells to keep them functioning properly. This mechanism is also important for nerve cells in the brain where defective proteins can kill cells and cause the debilitating symptoms

*Continued on page 7, see "New Research"*

of Parkinson's, such as tremors, said Ana Maria Cuervo, a cell biologist who led the study.

"We have found in Parkinson's there are problems in removing abnormal proteins," said Cuervo of the Albert Einstein College of Medicine of Yeshiva University. The finding could potentially lead to drugs to treat the symptoms but not cure the disease. Cuervo had previously shown how mutant forms of a protein called alpha-synuclein, found in a percentage of Parkinson's patients, blocked the breakdown of substances and prevented cells from clearing damaged proteins.

In the study in the *Journal of Clinical Investigation*, the team showed how in the majority of patients dopamine modifies normal proteins to acts like the mutated ones to trigger tremors and other symptoms. "What we have found is dopamine modifies alpha-synuclein that really resembles the mutation," Cuervo said. "That is why they have the same symptoms."

Problems in this process have also been linked with other neurodegenerative conditions such as Alzheimer's and Huntington's disease, though the specific mechanisms that cause problems in those conditions are different, she said.

Cuervo said a drug to fix the breakdown in Parkinson's patients was years away because it would take researchers time to understand fully how the process worked. "This is not something that is going to lead to a treatment tomorrow," she said. "The hope is within five years we can get companies to find a drug able to activate this system."

### Hopes Rise Over Parkinson's

*Oxford Mail, December 2007*

Scientists at an Oxford biotech firm

are hoping they have made a breakthrough in the search for an effective Parkinson's disease treatment. Trials on the ProSavin gene therapy product, which has been developed by Oxford Biomedica based at the Oxford Science Park, have started in France, with experts confident of success. Chief Executive Professor Alan Kingsman said: "The product could represent a fundamentally new approach for the treatment of Parkinson's disease and could significantly expand the worldwide market for existing therapies."

He said the clinical trial followed more than 10 years of research. ProSavin uses gene therapy to restore dopamine production in the brain. Initial tests have shown almost complete recovery of movement and other behavior with a single treatment effective for at least two years. Current surgical approaches to treatment require the destruction of brain tissue or the use of electrodes to stimulate the brain.

### Nicotine Reduces Levodopa-Induced Dyskinesias

*Science Daily/Annals of Neurology, November 2007*

The Parkinson's Institute and Clinical Center has announced research showing that intermittent nicotine treatment reduces medication-induced dyskinesias by as much as 50% in models of Parkinson's disease. Long-term treatment with levodopa often lessens efficacy and causes multiple complications, including abnormal involuntary movements, called dyskinesias. Currently, there are only limited therapeutic options for dyskinesias, including reduction in levodopa doses, amantadine administration, and deep brain stimulation.

Most of the research on tobacco

has focused on its detrimental health effects. Studies conducted over the last 40 years show that the incidence of Parkinson's disease is about 50% less in smokers than in the general population. Recent studies in experimental models suggest that the nicotine in smoke may be responsible for this neuroprotective effect. In addition, this is the first research to show that nicotine may also reduce levodopa-induced dyskinesias. "Our hope is that this research represents a useful treatment strategy to reduce the dyskinesias that so many Parkinson's disease patients suffer," said Dr. Maryka Quick of the Parkinson's Institute and Clinical Center in Sunnyvale. "Reducing the side effects of levodopa makes it a much more effective and long-term treatment."

### Researchers Expect Groundbreaking Results

*The Netherlands, PRN Newswire, December, 2007*

Top Institute Pharma presented a new and highly promising research project on December 17, 2007. The TI Pharma project is a large-scale study into the brain material of Alzheimer's and Parkinson's patients, who gave permission to the Netherlands Brain Bank for their tissue to be used for scientific research. The analysis is a continuation of highly-promising results from previous studies and focuses on the genes that could be involved in the development of Alzheimer's disease and Parkinson's disease. The study that will form the basis for potential drugs is one of the largest to be carried out on an international level.

The project is being realized in cooperation with Solvay

*Continued on page 8, see "New Research"*

Pharmaceuticals, DNage B.V., the Netherlands Institute for Neuroscience, the Netherlands Brain Bank, VU University Amsterdam, VU Medical center, the Leiden University Medical Center, Utrecht University, University Medical Center Utrecht and the Erasmus MC in Rotterdam.

Principle investigator Joost Verhaagen of the Netherlands Institute for Neuroscience: "This study is unique in several aspects. Never before has such a large-scale study been carried out into Alzheimer's disease and Parkinson's disease. Moreover, we have been able to do research on people who did not yet know they had Alzheimer's disease or in whom the disease was only just starting. We can therefore follow the very first changes due to the disease as well as its progression. Additionally, this study is using rapidly-aging mouse models from DNage, in which Alzheimer and Parkinson-like symptoms spontaneously occur. We expect that this study will yield new insights in to the development of these diseases, and will therefore form the basis for potential drugs."

### **Lack of Glutathione Linked to Parkinson's Disease**

*Journal of Neuroscience, December 2007*

Researchers have shown in animal models that the lack of glutathione is linked to the development of Parkinson's disease. The study was led by Julie Anderson, PhD., from the Buck Institute for Age Research in Novato, California.

Glutathione is recognized as a potent detoxifying antioxidant that helps the body repair damage from stress, pollution, infection and damage. Scientists have shown in this

study that mice exhausting their levels of glutathione in dopamine-producing neurons developed nerve damage and symptoms that mimic Parkinson's disease in humans. In this study, genetically engineered mice were chemically induced to develop a depletion of glutathione in neurons as adults, and during different stages of adulthood. When the glutathione depletion was induced in young adults no Parkinson-like nerve damage occurred. When the depletion was induced in middle-aged and late-middle-aged mice, the loss of neurons specifically related to the onset of Parkinson's disease.

Researchers noted that loss of glutathione in neurons may have a strong effect on energy production in the sub cellular structure known as mitochondria. Glutathione is available as a dietary supplement, however, glutathione cannot pass the blood-brain barrier to reach glutathione-starving neurons, so no effect can be seen in Parkinson patients taking glutathione orally. Although previous studies have shown that glutathione was needed in certain areas of the brain in Parkinson's patients, according to the authors, this is the first time that a way to decrease glutathione synthesis in neural tissue by genetic manipulation has been achieved with the concomitant development of Parkinson's disease. The study points toward using glutathione as a therapeutic agent for the treatment of Parkinson's disease. From: *Inducible Alterations of Glutathione Levels in Adult Dopaminergic Midbrain Neurons Result in Nigrostriatal Degeneration.*

### **Chemical That Triggers Parkinson's Disease Discovered**

*ScienceDaily/Acta Neuropathologica November, 2007*

Researchers at the Saint Louis University School of Medicine have discovered the key brain chemical that causes Parkinson's disease – a breakthrough finding that could pave the way for new, far more effective therapies to treat one of the most common and debilitating neurological disorders.

Currently, the main approach for treating Parkinson's disease is to replace dopamine that's lost when the cells that produce it die off and cause the disorder. With this new research, however, scientists can better work toward neuroprotective therapies – those that actually block dopamine cells from dying off in the first place.

"We believe this work represents a very significant breakthrough in understanding the complicated chemical process that results in Parkinson's disease," said William J. Burke, M.D., Ph.D., professor of neurology at the Saint Louis University School of Medicine and the study's lead author. "For the first time, we've identified the chemical that triggers the events in the brain that cause this disorder," Burke added. "We believe these findings can be used to develop therapies that can actually stop or slow this process."

Parkinson's disease occurs when some nerve cells in the substantia nigra die or become impaired. Normally, these cells produce dopamine – a vital chemical that allows smooth, coordinated function of the body's muscles and movements. When about 80% of these

*Continued on page 9, see "New Research"*

# Gaining Control

**A** chronic illness changes your frame of reference; secure plans for the future may suddenly be overturned. The entire family unit may feel overwhelmed with new responsibilities and not know where to start. Here are some steps that may help you maintain balance and direction:

## Identify the challenges.

When you begin to get used to the day-to-day management of your or your loved ones's illness, consider more in-depth planning. Although it can be scary to look into the face of the prognosis, it can also help you regain control. Take stock, together, of your wants, needs and abilities to accomplish them. When you plan carefully you may find that something you thought was impossible might very well be feasible.

## Learn how to relieve tensions.

The intense stresses that come with the diagnosis now can become less intense, but are chronic companions of both caregiver and carereceiver. To keep tensions at bay, recognize and communicate how you feel. Keep up with your favorite hobby or activity, and keep some time for private reflection and rest.

## Understand your own coping process.

Don't expect that overnight you'll accept your illness, or the illness of your loved one. Parkinson's disease will put new strains on you and your family, and adjusting to these changes will be a challenge.

Sharing information about your health with people other than your doctors can be difficult, but is imperative. Long-term conditions like Parkinson's disease put extra burdens on families and communities. People

often don't know what to do or how to help, even though many want to.

Some of the important things to talk about with others include:

**Asking for help** – Most of us are reluctant to ask for help. We think it makes us weak, or we don't want to impose on others. But people want to help, because they want to make a difference in your life, and because it makes them feel good about themselves. Friends and family won't know what to do if we don't tell them. They may offer help when it's not needed or try to assist you in unhelpful ways. Only you can tell people what you need!

**Setting limits** – Learn how to say "no" and mean it. First, begin to say "no" to things that sap crucial energy or take away time you need for yourself. This is saying "no" to people who want you to do something for them. Second, learn how to say "no" to people who try to do much FOR you. It is crucial that you continue to do as much as you can for yourself, and to push yourself to live as independently as you can.

**Talking about emotions and symptoms** – It's stressful for families if they don't know how you're feeling. They can guess, but they don't know unless you tell them. Learn to express emotions and describe your symptoms clearly. For example, you might want to give your pain, fatigue or depression a number between 1 and 10. This will allow you to let people know how you are feeling, without overburdening your listener. Remember to listen to other's problems and fears too – and remember to celebrate milestones large and small.

## *New Research, continued from page 8*

dopamine-producing cells dies or are damaged, the symptoms of Parkinson's disease begin to appear.

Scientists have long known that a key protein called alpha-synuclein plays a role in the development of Parkinson's disease. Alpha-synuclein is found throughout the brain – but in some people the protein clumps together. This causes the death of the dopamine-producing cells, which in turn causes Parkinson's to develop.

The SLU researchers discovered that dopamine itself actually plays a role in destroying the cells that produce it. In the process that leads to Parkinson's disease, dopamine is converted into a highly toxic chemical called DOPAL. Using test-tube, cell-culture and animal models, the researchers found that it is DOPAL that causes alpha-synuclein protein in the brain to clump together, which in turn triggers the death of dopamine-producing cells and leads

to Parkinson's.

"This is very exciting," Burke said. "This is the first time that anyone has ever established that it is a naturally occurring byproduct of dopamine that causes alpha-synuclein to aggregate or clump together. It's actually DOPAL that kicks this whole process off and results in Parkinson's disease.

# Using the Internet

Recent studies from the Pew Internet and American Life Project have found that more and more Americans use the Internet to seek health information for chronic conditions and to look for answers to their health questions. In fact, the Internet now ranks just behind doctors as the primary source of what consumers perceive as useful and credible health information. Generally speaking, consumers rate themselves as “very satisfied” with the health information they obtain from web searches and sites. That is not to say that all of the health information on the web is of high quality; rather that consumers feel that they are able to identify the credible websites, or that they are able to seek input from their health care providers to evaluate the information they find.

Many organizations offer tips to consumers for evaluating health-related web sites. The list below contains the most commonly recommended questions to ask when evaluating health information on the Internet:

- Who runs the website? Can you contact them?
- How is the website paid for? Are advertisements clearly labeled?
- Why was the website created?
- Where does the content come from?
- How is new content selected?
- Do experts review content included on the website?
- Is the content up-to-date?
- Does the website ask you to share personal information? If so, what is their privacy policy? Do they sell names to advertisers or marketers?
- Are consumers encouraged to talk to their health care providers about the information they find on the website?

To help people find health information on the Internet, the Federal Government’s Department of Health and Human Services has developed *Healthfinder* ([www.healthfinder.gov](http://www.healthfinder.gov)). This site serves as a gateway or point of entry to the broad range of consumer health information resources available.

*Healthfinder* includes a searchable index and locator aids for news, publications, on-line journals, support and self-help groups, on-line discussions, and toll-free numbers.

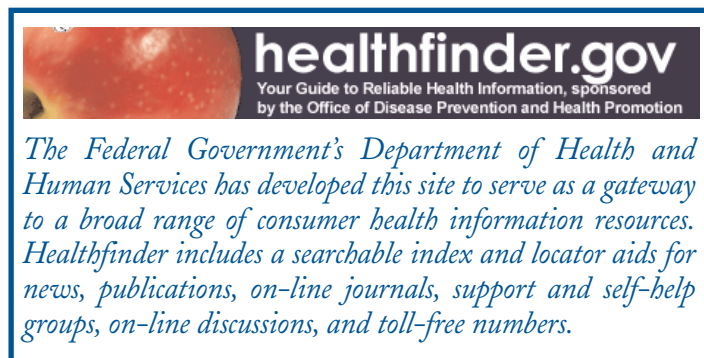
Don’t believe everything you read! Articles published in peer-reviewed medical journals are checked for accuracy, but anyone can put information on the Internet, so there’s no guarantee that the information you find is accurate or up-to-date. In addition, many companies set up sites primarily to sell their products. It may be helpful to ask a health professional about the information you find on the Internet, particularly

before you buy any products. Ask yourself whether the information or advice seems to contradict what you’ve learned from your doctor. If so, talk to your doctor to clarify the differences in the information. Be cautious when using information found on bulletin boards or during

“chat” sessions with others. Testimonials and personal stories are based on one person’s experience rather than on objective facts or proven medical research.

Medical information, especially material written for health care providers, can be hard to understand, confusing and sometimes frightening. As you read through your materials, write down any words or information you don’t understand or find confusing. Make a list of your questions and concerns. During your next office visit, ask your doctor, nurse or other health professional to review the information with you so that you understand clearly how it might be helpful to you.

Ultimately, the information you gather from print and electronic resources can help you make decisions about your health care. Armed with knowledge, you can more actively work in partnership with your doctor and other health care professionals to explore treatment options and make health care decisions. Health care experts predict that today’s computer and telecommunications systems will result in a new era built around savvy, responsible consumers who are the primary managers of their own health and medical care.



# Managing the Financial Crunch

Those of you that have recently become an elderly caregiver or maybe you're the well spouse may have to make up for the income that once was two that has now become one. You may feel like you have to take care of all the financial decisions and this can be a real burden. However, if you **know your options** this can be an easier transition than one might think. One should include as many family members as possible to make this transition so the burden doesn't lay solely on one person. The individuals involved should look into what things they need to plan ahead for: insurance, Medicare, savings plans, etc. One may want to involve a lawyer or get a financial advisor to help with these types of decisions. **READ THE FINE PRINT** on all insurance and disability plans and make sure the one you choose is the right one for you and your budget.

Be sure to **keep careful records** and copies. This is a really good idea especially for insurance bills, hospital records and needed prescriptions. Make sure to accurately label files and folders so they are easy to find and obtain when needed. Again one might want to talk to a financial advisor because some of these bills can be tax deductible.

One might think about **working from home** if they can't continue to work full time. Home based sales positions are available on-line or possible some consulting jobs for those who qualify.

It is very important that one research and **find low-cost services**. One can find this information at your local department of human resources, office of vocation and rehabilitation, or aging organizations may offer information on low cost respite services or even volunteer respite services. Also one might want to research for any local caregiver support groups. Also family members might be able to help with the cost of care. It never hurts to ask them!

**Make friends with similar needs** these are a good way to fine information on what has worked for others. Use these people as resource for what has worked for them in the past. One might find it easy to trade chores with these friends if they are close to one another; like exchanging shopping lists. Remember there is power in numbers and you are not alone.

*(Adopted from elderlyadvocates.com)*

## Ten Tips for Family Caregivers

Care giving is a job and respite is you're earned right. Reward yourself with respite breaks.

Watch out for signs of depression, and don't delay in getting professional help when you need it.

When people offer help, accept the offer and suggest specific things they can do.

Educate yourself about your loved one's condition and how to communicate effectively with doctors

There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.

Trust your instincts. Most of the time they'll lead you in the right direction.

Care givers often do a lot of lifting, pushing, and pulling. Be good to your back.

Grieve your losses, and then allow yourself to dream new dreams.

Seek support from other caregivers. There is great strength in knowing you are not alone.

Stand up for your rights as a caregiver and a citizen.

*– National Caregivers Association 2007*

# Heartland Support Group Meetings

(Listed by State)

## Kansas Support Groups

### Brown County (Hiawatha)

Second Thursday, 3-4:00 pm  
Light House Hospice  
Hiawatha Community Hospital  
(conference center)  
300 Utah  
Leigh Ann Schultejeans.....785.486.3881

### Clay County (Clay Center)

Third Tuesday, 2:00 pm  
First Baptist Church  
5<sup>th</sup> & Dexter  
Jewell Robinson .....785.632.3957

### Dickenson County (Abilene)

Third Tuesday, 2:00 pm  
Sterling House Abilene  
1102 North Vine Street  
Mary Jo Berg.....785.263.7800

### Douglas County (Lawrence)

Third Tuesday, 2:00 pm  
First Presbyterian Church  
2415 Clinton Parkway  
Mary Jane Clement .....785.865.2450

### Ellis County (Hays)

First Wednesday, 11-1:00 pm  
Hayes Medical Center  
Education Room  
2220 Canterbury Drive  
Paula Desbien .....785.726.3540

### Ford County (Dodge City)

Third Tuesday, 6:30 pm  
Fort Dodge, Eisenhower Hall  
Mike Kibler.....620.682.5846

### Harvey County (Newton)

Second Monday, 9:45-11:00 am  
Kidron-Bethal Retirement Center  
500 West Bluestem  
Community Room  
Kay Penner.....316.283.3948

### Johnson County (Prairie Village)

Third Monday, 1- 3:00 pm  
Brighton Gardens  
7105 Mission Road  
PFH .....913.341.8828

### Johnson County (Overland Park)

Third Thursday, 2:30 pm  
Freedom Point  
9201 Foster  
Eddie Johnson.....913.385.2052

### Johnson County (Overland Park)

**NEW!**  
Second Tuesday, 4-5:30 pm  
EVEN months  
Progressive Supranuclear Palsy  
7800 Foster  
PFH .....913.341.8828

### Johnson County (Overland Park)

Second Tuesday, 7:00 pm  
The Forum  
3501 West 95<sup>th</sup> Street  
Maryem Floyd .....913.341.8828

### Johnson County (Overland Park)

First Monday, 12:00 pm / Sack lunch  
Families of People with Late Stage PD  
7800 Foster  
PFH .....913.341.8828

### Johnson County (South)

Second Wednesday, 10-11:30 am  
Sunrise Senior Living  
12500 West 135<sup>th</sup> Street  
Nancy Lucas.....913.685.3340

### Leavenworth County (Leavenworth)

Last Tuesday, 1:30 pm  
Leavenworth Homestead  
5150 Hughes Road  
Vicky Walker.....913.727.9600

### Lyon County (Emporia)

Third Wednesday, 1:30 pm  
Presbyterian Manor  
2300 Industrial Road  
Shirlee Ebberts.....620.794.5339

### Marshall County (Marysville)

Fourth Monday, 1:30 pm  
Community Memorial Health Center  
Marci Duensing.....785.562.3224

### McPherson County (McPherson)

Second Tuesday, 10 - 11:30am  
Prairie View  
1102 Hospital Drive  
Janell Clary.....620.245.5000

### Montgomery County (Coffeyville)

Third Tuesday, 4:30-? (sometimes  
7pm), EVEN months  
Windsor Place  
2921 West 1<sup>st</sup>  
Jaque Rooks.....620.251.5190x56

### Riley County (Manhattan)

First Monday, 1:30-3:15 pm  
Riley County Senior Center  
412 Leavenworth  
Larry Marcellus.....785.537.1937

### Saline County (Salina)

First Thursday, 1:30-3:00 pm  
First Presbyterian Church  
308 South 8th Street  
Becky Ewing.....785.825.8461

### Sedgwick County (Wichita)

First Tuesday, 2-4:00 pm  
Fourth Tuesday, 7:00 pm  
Senior Services Building  
200 South Walnut  
Dorothy Roush .....316.304.9280

### Shawnee County (Topeka)

First Thursday, 5:30 pm  
Midland Hospice Church  
200 Frazier Circle  
Rob Peppers .....785.273.9861  
(work) .....785.272.6397

**Wyandotte County**

Second Monday, 12:30 pm  
 Trinity Methodist Church  
 5010 Parallel Parkway  
 Chester Claibron.....913.287.3171

**Jackson County (Independence)**

Third Tuesday, 3-4:00 pm  
 Fountains at Greenbriar  
 2100 Swope Drive  
 Desiree Rogers .....816.257.5100 x103

**Nodaway County (Marysville)**

Third Thursday, 6:30 pm  
 (Jan., March, May, July, Sept & Oct.,  
 6:00 pm at A&G restaurant)  
 First Christian Church  
 201 West 3<sup>rd</sup> Street  
 Jennie Lamb.....660.582.4468



## Missouri Support Groups

**Boone County (Columbia)**

First Thursday, 4:00 pm  
 Senior Citizens Center  
 1121 Bus Loop 70E  
 Gerry Neely.....573.815.3554

**Camden County (Lake Ozark)**

Third Thursday, 5:30- 7:00 pm  
 Lake Ozark Christian Church  
 Bagnell Boulevard, on the strip  
 David/Patsy Dalton .....573.964.6534

**Green County (Springfield)**

Last Wednesday, 3:30 pm  
 Cox Walnut Lawn (Senior group)  
 1000 East Walnut Lawn, Ozark room  
 Judae Steward.....417.269.3616

**Green County (Springfield)**

Fourth Thursday, 7:00 pm  
 Cox Walnut Lawn (Young Onset)  
 1000 East Walnut Lawn  
 Janice McCauley .....417.269.3616

**Grundy County (Trenton)**

First Thursday, 10:30am  
 Grundy County Health Department  
 Lower Level Meeting Room  
 1716 Lincoln Rear  
 Gloria Koon .....660.485.6558

**Henry County (Clinton)**

Second Tuesday, 1:30 pm  
 Clinton Community Center  
 1004 East Sedalia Center  
 Jeanette Fuhr .....660.885.4099

**Jackson County (Kansas City)**

Fourth Monday, 3:00 pm  
 Villa Ventura  
 12100 Wornal Road  
 Barb Messick.....816.941.0525

**Jackson County (Lee's Summit)**

Fourth Wednesday, 10:00 am  
 John Knox Places Restaurant  
 1001 Chipman Road  
 Dr. Kelly Lyons.....913.588.7159

**Jasper County (Joplin)**

Quarterly (April - October)  
 Contact for times  
 Caregiver and Parkinsons  
 2727 McClelland Drive  
 Vicki Lasure .....417.659.6544

**Jasper County (Joplin)**

Third Thursday, 10:00 am  
 Spring River Christian Village  
 201 Northpark Lane  
 Chantel Hamilton, RN .....417.623.4313

**Kansas City (North)**

Fourth Tuesday, 1:30-3:00 pm  
 St. Luke's Presbyterian Church  
 4301 Northeast Vivion Road  
 Berta Decena.....817.681.5010

**Kansas City (North)**

Second Thursday, 2-3:30 pm  
 Gardens at Barry Road  
 8300 Northwest Barry Road  
 Berta Decena.....817.681.5010

**Pettis County (Sedalia)**

Third Monday, 4:00 pm  
 First Christian Church  
 200 South Limit (Highway 65)  
 Barbara Schulz .....660.826.6039

**Raymore/Cass County**

Fourth Monday, 10:00 am  
 Foxwood Springs/Bromwell Lounge  
 1500 West Foxwood Drive  
 Jane Dodson.....816.322.0413

**Taney County (Branson)**

Second Thursday, 2:00 pm  
 Skaggs Community Health Center  
 251 Skaggs Road  
 Charlene Stade.....417.883.0637

*Continued on page 14, see "Listings"*

## Oklahoma Support Groups

### Clinton/Weatherford, Oklahoma

Second Thursday, 5:30 pm  
United Methodist Retirement &  
Health Center, Solarium Room  
2316 West Modelle Avenue  
Rhonda Gossen.....580.772.1818

### Edmond, Oklahoma

Second Tuesday, 3:30 pm  
Bradford Village, community center  
300 Enz Drive  
Contact Juli Rogers.....405.348.6945

### Enid, Oklahoma

First Wednesday, 2:00 pm  
Integris Pavilion cafeteria  
401 South Third Street  
Anita Andrew .....580.548.1110

### Grand Lake Area, Oklahoma

Fourth Tuesday, 6:30 pm  
Grove Community Center  
Highway 59 and Grand  
Rovia Collis.....918.787.2835

### Hugo, Oklahoma

Second Saturday, 2:00 pm  
Lane Frost Rehab Center  
2815 East Jackson  
Linda Edge .....580.326.0873  
Martha Hinnergardt .....580.326.9195

### Kingfisher, Oklahoma

Third Thursday, 6:30 pm  
Country Wood Manor  
1604 South 13<sup>th</sup> Street  
Dolores Greving.....405.263.4456

### Lawton, Oklahoma

Second Wednesday, 3:00 pm  
Ten Oaks Retirement Community  
3610 Southeast Huntington Circle  
Rose Hailey .....580.585.6640

### McAlester, Oklahoma

First Thursday, 6:00 pm  
Wellness Center  
1400 East Van Buren  
Dana Hugle.....918.421.8626

### Midwest City, Oklahoma

Fourth Thursday, 2:00 pm  
Senior Center  
8251 East Reno  
Rosemary Keating.....405.607.0940.

### Norman, Oklahoma

First Thursday, 7:00 pm  
Norman Regional Hospital,  
Education Wing  
901 North Porter  
Dr. Francis Schmitz .....405.364.4493  
Jack Shadle.....405.321.1274

### Far North Oklahoma City

First Wednesday, 2:15 pm  
Flora Deen Martin Center, Epworth Villa  
14901 North Pennsylvania  
Enter from Northwest 150<sup>th</sup> Street  
Bob Cunningham .....721.5345

### South Oklahoma City

Third Tuesday, 3:30 pm  
Jim Thorpe Rehab, Jones Education room  
4219 South Western  
Lori Smith .....405.644.5262

### Ponca City

Second Friday, 10:30 am  
Via Christi at Home  
1209 East Prospect  
Dianna Gemmill.....580.765.8155

### Stillwater, Oklahoma

First Tuesday, 2:00 pm  
First Nazarene Church  
1023 East Will Rogers  
Cathy Jordan .....405.742.5787

### Tulsa, Oklahoma South

Fourth Tuesday, 6:00 pm  
University Village  
8555 South Lewis  
Sherri Brown.....918.298.3652

### Tulsa, Oklahoma Southeast

Third Thursday, 6:30 pm  
St. Francis Hospital, Heart Center  
6151 South Yale  
Dave McCabe .....918.625.5255

### Woodward, Oklahoma

Third Wednesday, 2:00 pm  
Grace Living Center  
429 East Downs  
Pam Kenneaster .....580.256.6448

### Yukon, Oklahoma

Second Friday, 1:00 pm  
Spanish Cove  
1401 South Cornwell  
Dr. Deketia Murphy .....405.354.2439

**Young/Newly Diagnosed Parkinson Group** meets quarterly in Oklahoma City. For meeting times and location, contact Jim Keating at 405-810-0695.

# Exercise Groups

## Kansas Exercise Groups

### Olathe, KS

Mondays, 10:00 – 11:00 am  
First Baptist Church  
151<sup>st</sup> and Mur-Len Road  
Monica Moll.....913.856.8130

### Kansas City, KS

Mondays, 11:00 am – 12:00 pm  
Trinity Methodist Church  
5010 Parallel Parkway  
Chester Claiborn ...913.287.3171

## Missouri Exercise Groups

### Kansas City, MO

Mondays, 9:30 – 10:30 am  
North Cross United Methodist Church  
1321 Northeast Vivion Road  
Lyle Evans .....816.452.4485

Tuesdays, Thursdays & Saturdays,  
9:30 – 10:30 am  
Garden Village, Fourth Floor  
8550 Granby  
Mary Jane Branch....816.436.5555

Tuesdays & Thursdays  
1:00 – 2:00 pm  
Valley Center, Kansas  
117 South Park  
Cinda Garcia.....316.755.1115

Mondays & Wednesdays,  
10:30 – 11:30  
Gardens at Barry Road  
8300 Northwest Barry Road  
Karen Carmack.....816.584.3200

**NEW!**

Balance and Coordination Class  
Tuesdays & Thursdays,  
1:00 – 2:00 pm  
Kingswood Senior Living  
10000 Wornall Road  
Ray Gilliland.....816.942.0994

## Oklahoma Exercise Groups

### Edmond, OK

Tuesdays, 1:00 pm  
Bradford Village  
300 Enz Drive, in the  
community center.  
Laura Pollard.....405.341.0810

### Norman, OK

Tuesdays & Thursdays, 10:30 am  
First Baptist Church  
Family Life Center  
300 West Comanche  
Dr. Francis Schmitz...405.364.4493  
or Jack Shadle.....405.321.1274

### Oklahoma City, OK

Tuesdays & Thursdays, 12 noon  
NeuroScience Institute at  
Mercy Health Center  
4120 West Memorial Road  
in the atrium on the first floor  
Ms. Kay Oglesby.....405.752.3968

### Oklahoma City Water Exercises/Central

Wednesdays, 12 noon to 1:00 pm  
Valir Rehab  
700 Northwest 7<sup>th</sup> Street  
\$4/session or 10 sessions/\$35  
Margaret Kierl.....405.553.1050

### Oklahoma City Water Exercises/South

Mondays, Tuesdays & Thursdays,  
various times  
Jim Thorpe Rehab indoor pool  
4219 South Western  
Andrew Heuser .....405.644.5293

### Tulsa, Oklahoma

Mondays, Wednesdays & Fridays  
University Village  
8555 South Lewis  
\$35 per month fee  
Missie Moore .....918.299.2661

Contact Jim Keating, Director, for more information at 405-810-0695  
or e-mail [jim@parkinsonheartland.org](mailto:jim@parkinsonheartland.org).



**PARKINSON FOUNDATION  
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**Jim Keating**

*Oklahoma State Director*

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Phone/Fax: 405.810.0695

Our newsletter is published by the Parkinson Foundation of the Heartland to help People with Parkinson's, their relatives and their friends. It is not intended to provide personal medical advice, which should be obtained directly from a physician. Contact us at the Foundation office if you have suggestions as to how we can better serve you.

# Spring Events

## Step Up! Step Out!! For Parkinson's

### **The BasketBALL**

**April 5<sup>th</sup>**

**Overland Park Sheraton**

**4:30pm**

Join us for our signature fundraising event, featuring drinks and dinner, a casino, live auction, and the Final Four games on big screen TV's. Special guests from the Harlem Globetrotters will perform basketball tricks and sign autographs.

### **The Symposium**

**April 12<sup>th</sup>**

**Johnson County Community College**

**Noon**

Watch your mail for information on this year's Research Symposium and these other upcoming events:

### **Cruisin Down Memory Lane Classic Car Show and Parade**

**April 10<sup>th</sup>**

**Brighton Gardens by Sunrise**

### **Steps to the Cure 5K Run**

**April 18<sup>th</sup>**

**Lions Gate Marketplace**

**8 am**

### **The Don Klein Memorial Golf Tournament**

**April 24<sup>th</sup>**

**Falcon Ridge Golf Club**

### **The Town Art Show**

**June 13<sup>th</sup>, 14<sup>th</sup> and 15<sup>th</sup>**

**Town Center Plaza**

**PARKINSON FOUNDATION OF THE HEARTLAND**

7800 Foster  
Overland Park, KS  
66204-2955

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