



PARKINSON UPDATE

Serving Kansas, Missouri and Oklahoma

Spring 2007

Making Informed Choices

As the *Update* goes to press, we are nearly halfway through our traditional season of fundraising events. It's been a busy and profitable spring for us – with more to come. We'd like to take a moment to thank a few of the many people who make it possible for us to continue to serve you. None of these people did their jobs alone, but all played absolutely critical roles in our effort.

Rick Lucas ran this year's *BasketBALL* and made it the most profitable in our history. This is a huge job, and Rick performed with grace and good humor under great pressure. Thanks also to Rick Kastner, who so ably headed up our Corporate Sponsorship effort. Our sponsors are people and companies who care about Parkinson's disease and our efforts.

We are grateful to Drs. Pahwa, Lyons and Nazzaro for their terrific job at our *Annual Bi-State Symposium*, and to the people at Johnson County Community College for their donation of space.

Sally Stuart again put on a fun and memorable *Car Show* ... and has agreed to co-chair the 2008 *BasketBALL*! She is a dear friend of the Foundation, and we feel lucky to know her.

Jen King, with a major assist from Katie Fuchs, did an amazing job on this year's *5K run*. The event went off without a hitch and everyone had a great time! The Amazing Sweeney girls – Brenna and Corey – Betty Burum and Debbie Rubin are our top individual fundraisers. Thank you.

We have some incredible events coming up. *The Town Art Show* will be again held on Father's Day Weekend, June 15th, 16th and 17th. If you haven't made it to the show, try to come this year and enjoy art, music and food. As always, we are deeply indebted to Bill and Sue Hunter who make this event possible and selflessly give so much to us each year.

In August, Suzanne Dimmel and her committee are inaugurating a fabulous new event, "*The Classmen and Friends, Kansas City's Greatest Reunion Jam*." The event will be held on August 24th at the H&R Block Headquarters, and will feature local rock bands from the 60's and 70's. Join us for food, drinks and dancing. For more information, please visit [www. KCReunionJam.com](http://www.KCReunionJam.com), or call the office.

In September, the Parkinson Foundation will be a beneficiary of the Greek Orthodox Church of the Annunciation's annual *Greek Food*

Festival. This is an enormous event with the most delicious and authentic Greek entrees, pastries and music in town. Join us at 120th and Wornall Road on September 7th, 8th and 9th.

Finally, in December of this year, we are a proud beneficiary of the *Kappa Kappa Gamma House Tour*. We'll update you on this fun and festive event in future issues.

These people, with the hard-working board and staff of the Foundation, make so much possible. These events will allow us to provide hundreds and hundreds of hours of programs and services, and to make a meaningful contribution to the on-going efforts of many to cure Parkinson's disease. Their efforts also help us to cover the cost of writing, printing and mailing this *Update* to you.

In this issue, you'll find articles about long-term insurance, Medicare Part D, making the decision to move to a long-term care facility, seeing an elder lawyer and more! We hope that you enjoy receiving and reading our newsletter – we certainly enjoy putting it together and discovering things that might be of interest to you. If there is a subject you would like us to address (or a program or service you would like us to offer) please call and let us know.

PARKINSON FOUNDATION OF THE HEARTLAND

From The Chairman



Drew Dimmel
Chairman
dimmel@everestkc.net
(913) 269-7821

Choosing a Doctor

During the onset of my Parkinson's (you know, the years when "something" wasn't right...I just couldn't put my finger on "what" was wrong) I went through four neurologists whose diagnoses included: depression, exhaustion, bi-polar disorder and, finally, nervous and "fidgety." With no predisposition for Parkinson's Disease in my gene-pool, I had no idea what I had. Obviously, the first four of my five neurologists didn't either. Until I saw a neurologist specializing in Parkinson's Disease, I did not receive the correct diagnosis or treatment. In view of my "one-out-of-five" batting average in choosing the right doctor ... I should have chosen more carefully.



Selection of a doctor is often made from a list of managed care network physicians with the decision based on the sound of the physician's name or the location of the physician's office.

Factors To Consider

Medical societies and consumer groups say that your decision should include important, available information such as a doctor's:

- academic history
- board-certification
- continuing medical education
- hospital affiliations

Academic History

It is helpful to know the doctor's specialty and subspecialty (the areas in which a doctor received between three to seven years of additional training beyond medical school). For example, my doctor, Dr. Rajesh Pahwa, is a board certified neurologist who completed additional training specifically in the treatment of movement disorders such as Parkinson's disease and tremor disorders.

Board Certification And Continuing Education

A doctor who's board-certified has taken several extra years of specialty training and passed a rigorous board examination. Many boards require continuing education and periodic recertification.

Hospital Affiliations

Information about a doctor's hospital affiliations will tell you if the doctor has privileges at a particular hospital and also serves to attest to his credentials. It is recommended that your primary care doctor have privileges where your surgeon does. That way, the primary doctor can manage your general care following a surgical admission. For instance: at the KU Medical Center, my primary neurologist is Dr. Rajesh Pahwa. If I elect to have DBS implant surgery for my Parkinson's disease, my surgeon of choice, Dr. Jules Nazzaro, is also at KU Medical Center and they both have privileges at KU Hospital.

What You Need To Know Before Choosing A Doctor

The AMA recommends researching the following details when selecting a doctor:

- What are the doctors' office hours?
- What is his/her availability in an emergency (or a back-up physician)?
- How long is the average wait during appointments?
- How many patients are booked per hour?
- Can YOU choose the specialist you wish to see?
- Assess your general rapport with the doctor during an interview with him?
- When choosing a surgeon find out how often he performs your particular operation.
- How does this number compare to national standards?

... and, remember ...

Along with certification and credentials, it's just as important to FIND A DOCTOR WHO YOU CAN TRUST ... and with whom you have a good rapport. A combination of trust and competency is paramount to a good patient/physician relationship. It is obviously also important to know which doctors are covered by your insurance plan or HMO.

The AMAs "Doctor Finder" has information on 650,000 American doctors and is searchable by name, specialty, and location.

It is possible to find out whether a doctor has been fined or had his license suspended or revoked from the State Board of Medicine. The county courthouse offers information on lost malpractice suits, and there is also a book available called "Questionable Doctors" from the Public Citizens Health Research Group.

A lot of information is available about physicians...both good and bad. It's YOUR responsibility to check all the resources ... then CHOOSE THE RIGHT DOCTOR.

Health and Happiness,

Drew

Drew Dimmel
Chairman/Board of Directors
Parkinson Foundation of the Heartland

Long-Term Care Insurance – Making an Informed Choice

Few of us have long-term care insurance, but many of us will need it. Statistics show that two of three people turning 65 will eventually need long-term care at home, in an assisted living facility, or in skilled nursing. Longer life spans, the rising costs of health care, and an increasing reluctance to rely on family members who may work and live far from their loved ones are driving sales of these policies. About eight million long term care policies are currently in effect, a small number considering the population involved.

Deciding to buy a long-term care policy is only the first in a myriad of decisions to be made. The policies have many variables and can be very confusing. Below, we will attempt to address some of the questions we are most commonly asked – but this information is only meant to help you formulate questions to ask a financial planning or insurance professional.

Who should buy?

Many experts recommend that only those with assets of \$200,000 to \$4,000,000 should consider these policies — but this is an individual decision and depends on a variety of personal factors, such as your willingness to draw down your funds versus leaving them to future generations. Many believe that those with assets on the low-end of the scale will quickly reach spend-down and be able to access Medicaid and Medicare. Experts generally advise those with very high asset levels (above the

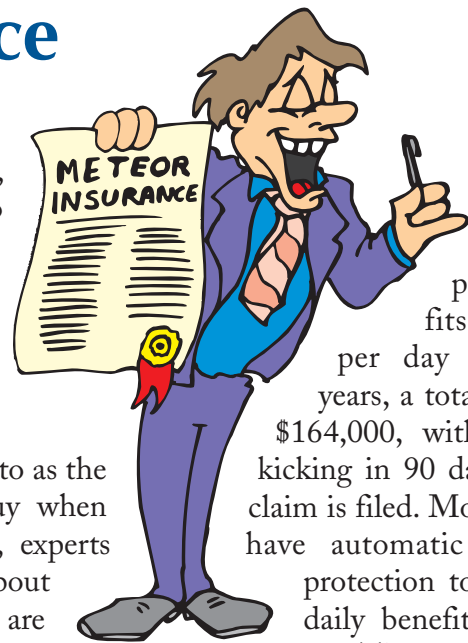
\$4,000,000 mark) to avoid long-term care insurance, as the costs of paying into the policy will not ultimately result in a savings.

When should you buy?

Insurance is often referred to as the one product you can't buy when you need it most. Again, experts recommend buying at about age 50, when most people are young and healthy enough to qualify for a modest premium. However, the average age of purchase is currently about 72: when only one in five qualify for good health discounts. Two-fifths of this age group are denied coverage at any price. Many insurance professionals recommend taking out a policy on the youngest or healthiest partner in a marriage, as this person may be left with no one to care for him or her. There are companies that will cover you even with a diagnosis of Parkinson's disease, though these policies are often very expensive, and a careful cost-benefit analysis is called for.

What does a typical policy cover/cost?

Healthy people generally get better rates on individual policies, those in poor health on a group plan. The long-term care industry leaders are John Hancock, MetLife, Mass Mutual, Prudential and Genworth. Always compare terms and prices of two or three different policies, and if you have the opportunity, a group plan. A typical John Hancock



policy for a 65 year old might pay benefits of \$150 per day for three years, a total of about \$164,000, with benefits kicking in 90 days after a claim is filed. Most policies have automatic inflation protection to raise the daily benefit 5% each year. The annual premium would be \$1,600 if you buy at age 50, \$1,840 if you buy at 55, \$2,233 at 60, \$2,845 at 65, \$4,225 at 70 and \$6,560 at age 75. Once you are placed in a risk category, your annual premium will not rise, regardless of your health status, unless the company has regulatory approval to raise premiums for all policy holders in your state.

You can customize a policy to almost any number of years of benefits, raise or lower the daily dollar amount, or customize the waiting period. Inflation protection can be purchased on a simple or compound basis. Premiums generally rise 8-9% per year you wait to apply, and will depend on which of the three main health-related risk categories you fall into. These are preferred, standard, or sub-standard. Premiums are also affected by whether you are married and if your spouse is also applying for a policy. Married people, and in some cases committed partners or siblings, often receive discounts

of 15-40% because they are presumed to have a care provider living with them.

What is the application process like?

It usually takes several weeks to be assigned a risk group and accepted into a long-term care policy. You will be asked to fill out an application and make statements about your general health. Usually, the insurance company will follow up with your medical provider. Most companies also do a phone interview. This interview will focus on your mental acuity, as insurers are typically less concerned with disease and conditions that shorten life span, and more concerned about conditions that may require care while allowing you to live a long life. The interviewer may ask you to name as many fruits or vegetables as you can, or do simple math calculations.

When can I file a claim?

Even though you can customize your long-term care plan, the insurance industry has standardized

its contracts. Most policies allow you to collect benefits when you are unable to perform two or three of six activities of daily living (ADLs). The ADLs are bathing, dressing, using the bathroom, continence and basic mobility. Be sure that this determination is made by your own medical practitioner, not by the insurance company. Benefits are paid under three methods. The most common is reimbursement, with the company paying you or your provider when you receive services the company deems eligible. The other methods are indemnity, when the insurer pays you a set amount directly as long as you obtain care, and disability, under which you get the full benefit whether or not you choose to use any services.

What questions should I ask?

Talk with your financial planner or insurance professional about the details of your policy. Ask about the benefit period, the amount of the daily benefit, inflation protection and the waiting period. Be sure to check into the financial strength of

the company, and its AM Best rating. Most people select a three-year benefit period, which experts consider a good, average policy. (Those of us with PD might want to increase the benefit period.) Women, on average, tend to use their policies for 3.7 years, compared to 2.2 years for men. Be sure you take the full benefit for home care. Dealing with a progressive illness at home, with individualized nursing care, can be far more expensive than is a skilled nursing facility.

And finally...

You can deduct long-term care premiums from your income taxes, providing that they and other medical expenses exceed 7.5% of your adjusted gross income. You can also save as much as 8% by paying premiums annually, instead of monthly or quarterly. Long-term care insurance is not for everyone, certainly not for those who can ill afford the premiums. Be sure to take the time you need to make a good decision for you and your family.

Upcoming Events

Town Art Show

June 15th, 16th and 17th

Town Center Plaza, Leawood KS

Enjoy an outdoor, juried fine art show featuring over 200 artists from around the U.S. More than 40,000 people attend the art show each year! Listen to great live music while enjoying refreshments and fine art.

The CLASSmen & Friends – Kansas City's Greatest Reunion Jam

August 24th, 2007 6 – 10:00 pm

H&R Block Headquarters – 1 H&R Block Way

Join us for food, drinks and great music at the H&R Block Art Space. This is a fun and exciting new event!



Medicare Part D – Good Coverage for Parkinson’s Patients?

The Medicare Modernization Act was launched in 2006 to mixed reviews. There were many initial problems including slow reimbursement to pharmacies, unexpected out of pocket costs for consumers, and a staggering number of confusing plan options. This year is expected to bring some improvements, including enhanced benefit plans, improved access to pharmaceutical benefits, and improved customer service.

Parkinson patients must pay close attention to the plan and benefit package they select. Because our drug regimens can be complex and changeable, we are particularly vulnerable to increasing costs. We must also be certain that we have access to the medications prescribed for us. When you are making a decision about which Prescription Drug Plan (PDP) or Medicare Advantage-Prescription Drug Plan (MA-PD) be sure you ask:

- What is the monthly premium?
- What is my deductible?
- What medications are included under the plan? (The Formulary)
- What kind of gap coverage does the plan offer?
- Which of my medications are subject to prior authorization, step therapy or quantity limits?

Most of the plans use a tiered cost-sharing system. Basically, this means that there is very little consumer expense for generic drugs, and increasingly higher consumer expense for specialty or branded products. Since most of our Parkinson medications reside on either the third or fourth tier, we incur substantially more out-of-pocket expenses.

Premiums for basic coverage are not expected to increase substantially in 2007. On average, the cost of Medicare Part D is expected to be about \$24.00 per

month, compared to \$20.00 in 2006. However, in 2007 we will have many more options for enhanced coverage with higher premiums. These programs will cost between \$50.00 and \$100.00 per month, and will offer lower annual deductibles, expanded formulary (more drug choices), higher coverage limits, and fewer out-of-pocket expenses. Some plans will cover the gap or “doughnut hole.” These are expected to cost about \$50.00 for generic drugs during the gap period, and \$100.00 for all drugs during the coverage gap.

The “doughnut hole” is of particular concern to Parkinson patients. Unfortunately, in 2007 the gap will increase from \$2,250 to \$2,400. Only about 3% of the available plans will cover both generic and branded drugs during the gap, and even then, they may not cover all Parkinson medications. Many more of the MA-PDs will offer gap coverage.

Some experts believe that the enhanced PDPs will offer the best benefits for Parkinson patients. However, each individual needs to line out the cost of their prescriptions with co-pay, deductible, cost of prescriptions during the coverage gap, (check to be sure that all prescriptions will be covered) and weigh that against the cost of the premium.



Is It Time to See An Elder Law Attorney?



- What directions will you provide related to end-of-life decisions:
 - If you can no longer eat, drink or breath on your own
 - If you cannot function independent of machines
 - If you have no cognitive ability

What is a living will?

A living will is a statement of how an individual would like to be treated in the event that he or she cannot make decisions regarding the use of life-sustaining medical treatment. A living will can order the withdrawal or withholding of life-sustaining measures, or it can order continuous medical treatment regardless of your medical condition.

What is a health care proxy?

The health care proxy is the voice of the living will. It authorizes one or more individuals to communicate a client's wishes regarding end of life treatment. In its basic form, it does not provide any additional authority.

What is a Health Care Power of Attorney?

The health care power of attorney is the teeth of the living will. It not only authorizes an individual to communicate a client's medical instructions, but can provide a host of other powers in the appointment of an agent who can hire and discharge medical personnel and medical institutions. This agent is also authorized for access to your medical history, and can consent to a DNR (Do Not Resuscitate) order. The health care power of attorney can also be expanded to provide for decisions not related to the end of life, but that are necessary when a client may be otherwise incapacitated. Kansas and Oklahoma require the use of a mandatory form for advance directives, Missouri does not.

There is a lot more to getting your affairs in order than deciding on the disposition of your assets. The far more important consideration is figuring out who's going to help you manage things while you are still alive, but need assistance or are unable to act on your own behalf.

Visiting an elder law attorney to draw up a living will, health care proxy or health care power of attorney can be a real relief. If you prepare for the meeting and have thought through some of these questions, the process should be fast and smooth. Consider:

- Who will act as your agent of care? Who will serve as alternate?
- Are there certain medical treatments or pain control measures you want (or don't want)?
- Do you wish to take or refuse any medication that may reduce or eliminate your ability to communicate?
- Do you have any particular directions regarding specific health care facilities, religious preferences, disposition of your body, or donation of body parts for transplant or research?

Member Harold Hessman has a device that will help people get in and out of their cars. His device is perfect for a 2002 Ford Taurus, but can be retro-fitted for any car for about \$150.00. If you are interested in learning more about this equipment, please call Harold at 913-248-0254.

Choosing an Assisted Living Facility

Assisted living facilities provide supervision, assistance and personal care services to senior citizens and those with disabilities. Their goal is to maintain a warm, home-like setting, while providing individualized care and assistance.

Choosing the appropriate residential setting can make all the difference in an individual's mental, physical and social well being. People with Parkinson's disease should inform themselves about options in care to ensure that the assisted living facility they choose is appropriate to their particular needs.

Assisted living is part of a continuum of long-term care services that provides a combination of housing, personal care services and health care. Assisted living is designed to provide care while promoting maximum independence. Assisted living facilities may be integrated into skilled nursing homes or hospitals, be components of continuing care retirement communities, independent housing complexes or free-standing residences.

Assisted living facilities are required to "provide or coordinate a range of services identified in negotiated service agreements." Upon admission, a service plan should be developed to coordinate the delivery of services to each resident. The agreement, which includes an assessment or evaluation of the resident's physical and psychosocial needs, should be reviewed and updated regularly by the staff.

You and your family should play an active role in the development of the service plan. For people with Parkinson's disease, help with medication management and suitable exercise programs are very important.

Assisted living facilities are also required to complete a Resident Functional Capacity Screen before admission. This screening usually consists of a few questions about how independent you are in the Activities of Daily Living (bathing, dressing, eating, mobility) and the Instrumental Activities of Daily Living (cooking, shopping, money management, medical management, transportation.) You can expect to be asked questions about your memory and recall, and about your abilities to make decisions and to communicate. You can also expect questions about risk factors, including falls, problems seeing or hearing, or wandering and disruptive behaviors. This screening is used to determine which services will be included in your "Negotiated Service Agreement." It is very important that your Functional Capacity Screen is an accurate picture of your need for services.

If your Functional Capacity Screen indicates you need health care services, a Registered Nurse or Licensed Practical Nurse will



develop a "Health Care Service Plan" with you. This plan will specify any health care services provided or coordinated by the facility. Your Health Care Service Plan becomes part of your Negotiated Service Agreement.

People with Parkinson's should have a health care assessment completed before they move into a facility. We recommend that you ask your physician and/or neurologist to review your Functional Capacity Screen and Health Care Service Plan to sure they are accurate, fair and complete.

Once these plans are in place, the facility will prepare a "Negotiated Service Agreement." This agreement sets out the services you will receive, who will provide them, and the rates you will be charged. This agreement is critical! Be sure that all the information is in writing and that you understand the policies for rate changes and refunds. The Negotiated Service Agreement should include provisions for:

- 24-hour supervision (if necessary)
- Daily meal service
- Housekeeping and maintenance services
- Arrangements for transportation (medical, dental and social)
- Recreational and spiritual activities

Continued on page 9, see "Assisted Living"

New Device Aids in Lifting and Transferring

Advances in medical technologies have been dramatic in recent years. One thing that hasn't improved, however, is moving a patient back and forth from bed to chair. Patient transfer is a difficult process that is dangerous to both patient and caregiver. Transferring frequently results in injury to both. Many patients who could otherwise live in their own homes are often moved into nursing facilities because their caregiver can not lift and move them alone.

There is a new product available called the Barton Positioning and Transfer Solution. The Barton device allows one person to safely

and comfortably transfer from bed to chair and chair to bed. This system is basically a stretcher that transforms to a wheeled, reclining chair. The stretcher is placed next to the bed, a top sheet attaches to the transfer system, and the caregiver simply turns a crank which transfers the patient back and forth. A 120 lb. person can safely and easily transfer a 200 lb. person, without strain on the back or danger to the patient. The stretcher chair has a headrest, arm rests and elevating footrest and adjusts to an infinite number of positions. The design helps to ensure patient comfort and aids in circulation to the feet, legs, hands and arms.

The Barton Transfer System is available through private insurance, Medicaid and Medicare to those who qualify. If you are currently using a home health agency, ask them about getting the system through Medicare. If you do not use a home health agency, you can call Brian Lunceford at the Barton company directly at 816-333-2525. You will be asked a series of medical questions to qualify you for a certificate of medical necessity. Your doctor will need to write a prescription for the system, but Barton will pre-qualify you. You must be unable to get out of bed and transfer to a chair.

Assisted Living, continued from page 8

- Laundry and linen service
- Social services
- Medication management or assistance with self-administration of medications
- Personal care services — help with ADLs
- Supervision for people with dementia and disability
- Exercise and wellness programs
- Supervised nursing care
- Coordination of skilled nursing care on an intermittent or limited term basis (i.e. recuperation from an illness or rehabilitation from a fall)

The costs of assisted living vary greatly, and depend on the size of

the room, amenities, services provided, location and the elements of your Negotiated Service Agreement. Calculating the approximate cost is important, as is understanding what happens if private, personal funds are depleted. While Medicare does not cover assisted living, certain health care services may be available. Supplemental Security Income may cover some costs and residences may participate in grant programs, the Medicaid program or offer assistance programs.

Several private health and long term care insurance policies include assisted living/residential coverage. However, the majority of assisted living costs are currently paid through personal finances.

Facilities should willingly provide consumers with key information regarding base rates, specific fees for additional services, occupancy levels, staffing and ownership. Obtaining information is crucial in choosing the appropriate assisted living or residential care facility. The Parkinson Foundation has "A Parkinson Patient's Guide to Choosing an Assisted Living Facility." This guide contains 40 questions to ask, an assisted living cost calculator, and a final checklist for use prior to signing the contract. Each guide has room for three different facilities, so you will have the information at your fingertips to make an informed choice. Call the office for your free copy.

Exercise Groups

Kansas Exercise Groups

Olathe, KS

Mondays, 10:00 – 11:00 am
First Baptist Church
151st and Mur-Len Road
Monica Moll913.856.8130

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 Evans816.452.4485

Tuesdays, 9:30 – 10:30 am
&

Saturdays, 9:30 – 10:30 am
Garden Village, Fourth Floor
8550 Granby
Mildred Laughlin816.468.6163

Tuesdays, 1:00 – 2:00 pm
&
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 7th 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 Heuser405.644.5293

Tulsa, Oklahoma

Mondays, Wednesdays & Fridays
University Village
8555 South Lewis
\$35 per month fee
Missie Moore918.299.2661

Contact Jim Keating, Director, for more information at 405-810-0695
or e-mail jim@parkinsonheartland.org.

Using the Internet Wisely

The internet is a wonderful tool. It brings the knowledge of the world into our homes, but it also opens our door to con artists and scammers. AARP recently listed the seven most common scams to watch for. They are:

“Phishing”

Con-artists look to gather personal information by asking consumers to “update” or “validate” their billing information, including credit card and Social Security Numbers. Many times, these e-mails will ask you to visit another website or call an 800 number. Beware! The websites may look real, but they are not. Many con-artists have begun to register 800 numbers and answer them with the fraudulent name. Never reply to these e-mails.

Foreign Money Offers

A “foreign government official” offers an opportunity to split a huge sum of money if he can just transfer funds to your bank account — and naturally, he needs your account information. These run the gamut from the ridiculous to the sophisticated. Smart people — and big banks — have been taken in by them. Do not respond in any way, except by hitting your delete button.

Sweepstakes

Very common, this scam tells consumers they have won something, and they need only pay a fee for processing, taxes or delivery to claim their prize. Sometimes they will offer to wire money into your account or send you a check to pay for the sweepstakes fee. If you give them your account number they will clean you out. If they send you a check, it will be fraudulent! Don’t respond!

Charity Fraud

This scam preys on the public’s generosity in giving to reputable charities by soliciting funds for disreputable or fraudulent ones. Always ask to have information mailed to you and tell anyone soliciting you that you will respond only to mailed information.

Foreign Lotteries

A call or letter tells consumers that they may have already won a big prize in a foreign lottery, obtainable merely by providing bank account or credit card information. Never, *ever* provide credit card or bank information to anyone.

Work at Home

This scam offers great payouts for little work at home, telling consumers they need only pay up-front supply, training or materials charges — charges they rarely recoup. One of the larger work at home companies sends information telling you how to place your own ads and recruit others to work at home — who then get the same information.

Medicare Enrollment

This scam is usually run in the early fall, in advance of Medicare’s November enrollment period. Con artists, sometimes purporting to be from insurance companies, try to get Social Security Numbers, credit card information and bank account numbers. Some offer to enroll people for a fee, even though there’s no charge to sign up. Be sure you select a reputable insurance agent to help you with your Medicare enrollment, and don’t respond to people who call or e-mail you.



Support Group Spotlight



The Parkinson Foundation facilitates over 75 support groups throughout our service area. In our winter *Update*, we discussed the importance of support groups to your well-being. Beginning with this issue of the *Update*, we will feature short sketches of each of our groups, in hopes of helping you choose the right group for you.

Caregivers of Late-Stage Parkinson Patients

This caregivers support group meets at the Parkinson Foundation of the Heartland offices on the first Monday of each month at 12:00 pm. Members bring a sack lunch. The group welcomes all those who are caring for a family member with late-stage Parkinson's disease. This is a discussion group that centers on the feelings caregivers commonly share; loneliness, fear, guilt, love. The group helps members understand that they are not alone and offers strategies for coping. Leader Betty Burum encourages all who feel they would benefit to join and learn from shared experiences. For more information, call Betty at 913.341.6746.

Clay Center Support Group

The Clay Center group meets on the third Tuesday of each month at 2:00 pm at the First Baptist Church in Clay Center. The church is located at 902 5th Street in the down town area. The Clay County group is a small but mighty group of twelve men and women. Members include farmers, health care workers, house wives and business men. The group normally watches a video and follow up with an open discussion. The Clay County group has room for more and welcomes new members. For more information, please contact Jewell Robinson at 785.632.3957.

Clinton Area Parkinson Support Group

The Clinton Area Support Group has been meeting since October of 2002, when Jeanette Fuhr realized her need to talk with other people with PD. Jeannette found Virginia Fowler, and the two formed the group. Through the aid of Tammy Woirhaye, Community Wellness Coordinator at Golden Valley memorial Hospital, the Clinton Group meets at the Clinton Community Center, located at 1004 East Sedalia and often has guest speakers and programs. Jeanette Fuhr serves as the program director and Darold Eberting leads the group. For more information, please contact Jeannette Fuhr at 660.885.4099.

Kansas City Area Evening Support Group

The Kansas City Area Evening Support Group started with people recently diagnosed with Parkinson's disease, and was called the Early

Kansas Support Groups

Brown County (Hiawatha)

Second Thursday, 3-4:00 pm
Light House Hospice
Hiawatha Community Hospital
(conference center)
300 Utah
Leigh Ann Schultejeans785.486.3881

Clay County (Clay Center)

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

Crawford County (Pittsburgh)

Third Thursday, 2:00 pm
Medical Lodge North
2614 North Rouse
Mavis Benner620.231.8741

Dickenson County (Abilene)

Third Tuesday, 2:00 pm
Sterling House Abilene
1102 North Vine Street
Mary Jo Berg.....785.231.8741

Douglas County (Lawrence)

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

Ellis County (Hayes)

First Wednesday
Hayes Medical Center, education room
2220 Canterbury Drive
Paula Desbien.....785.726.3540

Gove County (Quinter)

First Wednesday, 11:00 - 1:00 pm
Gove City Hospital
5th & Garfield
Mary Enstrom.....785.726.3540

Heartland Support Group Meetings

(Listed by State)

Harvey County (Newton)

Second Monday, 9:45-11:00 am
Kidron-Bethal Retirement Center
500 West Bluestem
Community Room
Kay Penner316.283.3948

Johnson County (Prairie Village)

Third Monday, 1- 3:00 pm
Brighton Gardens
7105 Mission Road
PFH913.341.8828

Johnson County (Overland Park)

Third Thursday, 2:00 pm
Freedom Point
9201 Foster
Amy Harberts913.385.2052

Johnson County (Overland Park)

Second Tuesday, 7:00 pm
The Forum
3501 West 95th Street
Maryem Floyd913.341.8828

Johnson County (Overland Park)

First Monday, 12:00 pm / Sack lunch
Families of People with Late Stage PD
7800 Foster
PFH913.341.8828

Johnson County (Overland Park)

Second Tuesday, 4-5:30 pm, even months
Progressive Supranuclear Palsy
7800 Foster
PFH913.341.8828

NEW!

Johnson County (South)

Second Wednesday, 10-11:30 am
Starting June 13
Sunrise Senior Living
12500 West 135th Street
Karey Simpson913-685-3340

Leavenworth County (Leavenworth)

Last Tuesday, 1:30 pm
Leavenworth Homestead
5150 Hughes Road
Vicky Walker913.727.9600

Lyon County (Emporia)

Third Wednesday, 1:30 pm
Emporia Senior Center
603 East 12th Avenue
Shirlee Ebberts620.583.5738

Marshall County (Marysville)

Fourth Monday, 1:30 pm
Community Memorial Health Center
Art Duensing785.562.3224

McPherson County (McPherson)

Second Tuesday, 10 - 11:30am
Prairie View
1102 Hospital Drive
Janell Clary620.245.5000

Montgomery County (Coffeyville)

Third Tuesday, 4:30-? (sometimes
7pm), EVEN months
Windsor Place
2921 West 1st
Jaque Rooks620.251.5190x56

Riley County (Manhattan)

First Monday, 1:30-3:15 pm
Riley County Senior Center
412 Leavenworth
Larry Marcellus785.537.1937

Saline County (Salina)

First Thursday, 1:30- 3:00 pm
First Presbyterian Church
308 South 8th Street
Becky Ewing785.825.8461

Sedgwick County (Wichita)

First Tuesday, 2-4:00 pm, &
Fourth Tuesday, 7:00 pm
Senior Services Building
200 South Walnut
Dorothy Roush316.304.9280

Shawnee County (Topeka)

First Thursday, 5:30 pm
Midland Hospice Church
200 Frazier Circle
Rob Pepper785.973.9861

Wyandotte County

Second Monday, 12-1:00 pm
Trinity Methodist Church
5010 Parallel Parkway
Chester Claibron913.287.3171

Missouri Support Groups

Boone County (Columbia)

First Thursday, 4:00 pm
Senior Citizens Center
1121 Bus Loop 70E
Gerry Neely573.815.3554

Camden County (Lake Ozark)

Third Thursday, 5:30- 7:00 pm
Lake Ozark Christian Church
Bagnell Boulevard, on the strip
David/Patsy Dalton573.964.6534

Green County (Springfield)

Last Wednesday, 3:30 pm
Cox Walnut Lawn (Senior group)
1000 East Walnut Lawn, Ozark room
Judee Steward417.269.3616

Green County (Springfield)

Fourth Thursday, 7:00 pm
Cox Walnut Lawn (Young Onset)
1000 East Walnut Lawn
Janice McCauley417.269.3616

Grundy County (Trenton)

First Thursday, 10:30am
Grundy County Health Department
lower level meeting room
1716 Lincoln Rear
Gloria Koon660.485.6558

Henry County (Clinton)

Second Tuesday, 1:30 pm
Clinton Community Center
1004 East Sedalia Center
Jeanette Fuhr660.885.4099

Continued on page 14, see "Listings"

Onset Group for many years. The group recently decided that “Early Onset” had grown to be a misnomer over the years, and changed their name. The group meets on the second Tuesday of each month from 7 – 9:00 pm at the Forum, 3501 West 95th Street in Johnson County. The group has an annual picnic each September, and a Christmas party each December.

There are usually about 25 attendees, and they often have a speaker who can shed some light on ways to cope with Parkinson’s disease. The Evening Support Group welcomes new members! The Forum furnishes drinks, coffee and cookies for each meeting. The group sends out a newsletter one week before each meeting. Please call Maryem Floyd at 913.341.8828 for more information.

Lee’s Summit Support Group

This group meets at John Knox Village on the fourth Wednesday of every month at 10:00 am in the Places Restaurant. Places is in the main information building of John Knox Village at 1001 Chipman Road in Lee’s Summit. The group is lead by Dr. Kelly Lyons who is Director of Research and Education at the Parkinson’s Disease and Movement Disorder Center at the University of Kansas Medical Center, and by Paul Budd who is the Chaplain at John Knox Village. The group occasionally has guest speakers; however, generally Dr. Lyons answers questions and discusses new treatments, ongoing research and new breakthroughs in Parkinson’s disease, encouraging group discussion. The group is comprised of people with Parkinson’s disease as well as caregivers and other family members Anyone affected by or interested in Parkinson’s disease is welcome to attend. For additional information, please call Dr. Lyons at 913.588.7159.

Sedalia Area Parkinson Support Group

The Sedalia Area Parkinson Support Group meets the third Monday of each month at 4:00 pm in Fellowship Hall of First Christian Church, 200 South Limit, Sedalia, MO. The group has about 15 active members, made up of people with Parkinson’s, caregivers and other interested people. Programs range from videos and guest speakers to discussion and pot luck dinners. Members Ida and Bill Shobe recently donated \$1,500 to the Parkinson Foundation of the Heartland from sales of a CD on which Bill sang. The group tries to “turn mope into cope” by supporting each other and learning all they can about Parkinson’s Disease. The Sedalia Area Parkinson Support Group is led by Barbara Schulz and welcomes new members. For more information, call Barbara at 660.826.6039.

Jackson County (Independence)
Third Tuesday, 3-4:00 pm
Fountains at Greenbriar
2100 Swope Drive
Desiree Rogers816.257.5100 x103

Jackson County (Kansas City)
Second Tuesday, 2:00 pm
Kingswood Senior Living Comm.
10000 Wornall Road
Deborah Rear.....816.442.3230

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 Lasure417.659.6544

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
Lyle Evans.....816.452.4485

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 3rd Street
Jennie Lamb.....660.582.4468

North Missouri (Marceline)

Contact for information
 Wallsworth Community Center
 124 East Ritchie
 Mrs. Clifford Freeman...660.376.3423
 Thomas Behrman660.376.3639

Pettis County (Sedalia)

Contact for information
 (Retiring need new leader)
 First Christian Church
 200 South Limit (Highway 65)
 Barbara Schulz660.826.6039

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
 Greenwalt Clinic
 Charlene Stade.....417.883.0637

**Kansas City (North)**

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

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 Andrew580.548.1110

Grand Lake Area, Oklahoma

Fourth Tuesday, 6:30 pm
 Grove Community Center
 Highway 59 and Grand
 Rovia Collis918.787.2835

Hugo, Oklahoma

Second Saturday, 2:00 pm
 Lane Frost Rehab Center
 2815 East Jackson
 Linda Edge580.326.0873
 Martha Hinnergardt580.326.9195

Kingfisher, Oklahoma

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

Lawton, Oklahoma

Second Wednesday, 3:00 pm
 Ten Oaks Retirement Community
 3610 Southeast Huntington Circle
 Rose Hailey580.585.6640

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 Keating405.607.0940.

Norman, Oklahoma

First Thursday, 7:00 pm
 Norman Regional Hospital,
 Education Wing
 901 North Porter
 Dr. Francis Schmitz405.364.4493
 Jack Shadle405.321.1274

Far North Oklahoma City

First Wednesday, 2:15 pm
 Flora Deen Martin Center, Epworth Villa
 14901 North Pennsylvania
 Enter from Northwest 150th 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 Gemmill580.765.8155

Stillwater, Oklahoma

First Tuesday, 2:00 pm
 First Nazarene Church
 1023 East Will Rogers
 Cathy Jordan405.742.5787

Tulsa, Oklahoma South

Fourth Tuesday, 6:00 pm
 University Village
 8555 South Lewis
 Sherri Brown918.298.3652

Tulsa, Oklahoma Southeast

Third Thursday, 6:30 pm
 St. Francis Hospital, Heart Center
 6151 South Yale
 Dave McCabe918.625.5255

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 Murphy405.354.2439

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

**PARKINSON FOUNDATION
OF THE HEARTLAND
(KANSAS)**

7800 Foster Overland Park, KS
66204-2955
913.341.8828 (tel.)
913.341.8885 (fax)
info@parkinsonheartland.org

Meg Duggan

Executive Director

meg@parkinsonheartland.org
913.341.8828 (tel.)
913.341.8885 (fax)

Mike Dreiling

President

mdreiling@levycraig.com
816.474.8181 (tel.)

Jennifer King

Program Director

jen@parkinsonheartland.org

Katie Fuchs

Program and Professional

Education Coordinator

katie@parkinsonheartland.org

**PARKINSON FOUNDATION
OF THE HEARTLAND
(OKLAHOMA)**

1000 West Wilshire Boulevard

Jim Keating

Oklahoma State Director

jim@parkinsonheartland.org
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.

Summer Programs

ABC of Parkinson's Disease

Are you or a family member newly diagnosed with Parkinson's disease? Would you like more information on PD, including common symptoms, treatments, and what the future may hold? If so, please join Dr. Kelly Lyons, Director of Research and Education at the Parkinson's Disease and Movement Disorder Center at the University of Kansas Medical Center.

Date: Coming Soon
PFH Offices: 7800 Foster, Overland Park
Information: Jennifer King.....913.341.8828

Wellness

Join us for an hour of specialized exercise instruction for people with Parkinson's. Participants will eat lunch with friends and enjoy the remaining time with planned recreational activities. Caregivers are encouraged to use this time for respite.

Tuesdays & Thursdays 10:30 – 1:00 pm \$5:00 per class includes lunch
PFH Offices: 7800 Foster, Overland Park
Information: Jennifer King.....913.341.8828

Northland Wellness

A wellness program designed to provide fitness, lunch and a time-out for caregivers.

Gladstone Fairview Christian Church 1800 NE 65th Street
Information: Frank Everett816.452.2829

Indoor Swimming

Join the Elder Spa Wellness Center at Village Shalom for group or individual water classes. Pool includes an underwater treadmill, shallow depth ideal for walking, hydro lift entering the water, and handrail around the perimeter of the pool.

Village Shalom \$20.00 per month, unlimited use, no contract
Overland Park 5500 West 123rd Street
Information: Village Shalom.....913.266.8409

Fall Exercise Study

If you are interested in joining a study of a seated exercise program specifically for Parkinson's disease, please call the office and we'll get you additional information.

PFH.....913.341.8828

PARKINSON FOUNDATION OF THE HEARTLAND

7800 Foster
Overland Park, KS
66204-2955

Non-Profit
U.S. Postage

PAID

Shawnee Mission,
Kansas
Permit No. 1268

Membership must be current to receive this newsletter.