

# The Informant



Newsletter of the American Parkinson Disease Association  
Information & Referral Center  
at Iowa Methodist Medical Center

Fall 2006



## The First APDA Golf Tournament

We'd like to thank each of you for your help and participation in making the APDA golf outing a big success. We have heard nothing but positive things from the golf participants and already have one hole sponsor for next year. With your help and support we raised over \$11,500. This event could not have taken place without you. Your help was greatly appreciated and we want to say thank you.

Thanks to the following sponsors and donor for their contributions to the success of the First APDA Golf Tournament.

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### **In this issue ...**

Coordinator's letter .....	2
President's letter .....	2
What to Know Before You Go	3
Support Groups .....	4
Art PD Style .....	4
Genetics of Parkinson's Disease .....	5
Zelapar® Approved .....	6
Exercise Classes .....	6
The Grace of Being a Caregiver .....	8
Video Available .....	8

The material in this newsletter is presented solely for the information of the reader. It is not intended for treatment purposes, but rather for discussion with the patient's physician.



Published quarterly by:  
APDA Information  
& Referral Center  
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All material related to Parkinson Disease contained in this newsletter is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's physician. Specific articles reflect the opinion of the writer and are not necessarily the opinion of the editor, the Information & Referral Center, the medical director of the Center or the APDA.

**From the Coordinator of the APDA Information & Referral Center,  
Iowa Methodist Medical Center, Des Moines – Sam Erwin**



The Information & Referral Center reaches out to 20 support groups and has increased our original 800 to over 1,200 copies of our newsletters to families and professionals throughout Iowa. Through the support of the chapter, we are also offering a recorded version of the June seminar to anyone who could not attend.

The I&R center also collaborated with the Des Moines Area Support Group to develop exercise classes on Mondays and Wednesdays (see page 6 to register).

For family members/caregivers we are offering you an opportunity in October to come together to discuss your challenges. When someone is diagnosed with Parkinson's disease, it is important to understand that support comes from many directions – friends, family, employers and medical professionals. Please take this as an invitation to contact us if you have a suggestion or individual who would be interested in helping us support the many people affected by this diagnosis.

**From the Iowa APDA Chapter President – Barbara Moore**

These past couple of months have been very harried for me, and I want to share this experience with you. It is very common for people with PD to fall at some point in the progression of the disease. This leads to viewing the ground as your enemy when fear is actually the real enemy. Fear leads to increase tightening of muscle and joints, which, in turn, leads to more injury incurred from the fall.



This is what happened to me – I fell hard on my shoulder and sustained a fracture. At first I could not understand why this fall had caused such an injury as people fall all the time and just get up and walk away. Now I know why, and I need to combat the real enemy – fear. Fearing loss of balance can actually cause you to lose your balance and fall. It has taken me awhile to figure this out – now I need to tackle overcoming this fear. I also figured out that I need some help.

I found that John Argue's book, "PD and the Art of Moving," can assist us in overcoming this fear and learning to love the ground and think of it as a safe haven. If you would like more information about this or other issues related to PD, please contact our Information & Referral center and ask for Sam (her contact information is at the top of the left column on this page).

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If you'd like to get involved in the Iowa APDA Chapter, contact Barbara Moore, via e-mail at [Barbara.moore@fbfifinancial.com](mailto:Barbara.moore@fbfifinancial.com), or write to Iowa APDA, PO Box 507, Waukee, Iowa 50263.

## What to know before you go ... Travel restrictions and information Effective Sept. 26, 2006

Prescription liquid medications and other liquids needed by persons with disabilities and medical conditions are allowed. This includes:

- All prescription and over-the-counter medications (liquid, gel, and aerosol), including KY jelly, eye drops, and saline solution for medicinal purposes.
- Liquids (to include water, juice, or liquid nutrition) or gels for passengers with a disability or medical condition.
- Life support and life sustaining liquids (bone marrow, blood products, transplant organs).
- Items used to augment the body for medical or cosmetic reasons (e.g. mastectomy products, prosthetic breasts, bras or shells) containing gels, saline solution, or other liquids.
- Gels or frozen liquids needed to cool disability or medically related items used by persons with disabilities or medical conditions.



Passengers with disabilities and medical conditions can choose to put their small bottles/items of liquid medication in a one-quart sealable bag (mixed with toiletries) without the need to declare these items. However, if the liquid medications are in volumes larger than 3 ozs each, they may not be placed in the quart-size bag and must be declared to a Transportation Security Officer. A declaration can be made verbally, in writing, or by a person's companion, caregiver, interpreter, or family member.

It is recommended (not required) that passengers bring along any supporting documentation (ID cards, letter from doctor, etc.) regarding their medication needs. It is also recommended, not required, that the label on prescription medications match the passengers boarding pass. If the name on prescription medication label does not match the name of the passenger, the passenger should expect to explain why to the security officers. Passengers are encouraged to limit quantities to what is needed for the duration of the flight.

Passengers are still be required to remove their shoes as part of the screening process, however, persons with disabilities, medical conditions and prosthetic devices **DO NOT** have to remove their shoes. Those who keep their shoes on will be subjected to additional screening that includes a visual/physical and explosive trace detection sampling of their footwear while the footwear remains on their feet.

TSA's checkpoint security screening procedures for persons with disabilities and medical conditions have not changed as a result of the current threat situation. All disability-related equipment, aids, and devices continue to be allowed through security checkpoints, once they are cleared through screening. Disability and medically related items permitted beyond the checkpoint include: wheelchairs; scooters; crutches; canes; walkers; prosthetic devices; casts; support braces; support appliances; service animals; any and all diabetes related medication, equipment, and supplies; orthopedic shoes; exterior medical devices; assistive/adaptive equipment; augmentation devices; ostomy supplies; medications and associated supplies; hearing aids; cochlear implants; tools for wheelchair disassembly/reassembly; personal supplemental oxygen; CPAP machines; respirators; CO2 personal oxygen concentrators; baby apnea monitors; Braille note takers; slate and stylus; tools for prosthetic devices; and any other disability-related equipment and associated supplies.



Overall guidance to travelers with disabilities is located on the web site of the Department of Homeland Security's Transportation Security Administration at: <http://www.tsa.gov>. This guidance includes disability/medical conditions specific tips. If you have additional concerns or questions you can also contact TSA's Call Center at 1-866-289-9673 or by email at [tsa-contactcenter@dhs.gov](mailto:tsa-contactcenter@dhs.gov)

## Parkinson Disease Support Groups

**P**arkinson's disease Support groups strive to replace negative attitudes and give a more realistic and clear understanding of the disease, as well as basic care and required treatment. These groups are designed to help patients and their families come to a better knowledge and understanding of the disease.

Support group members play a very important role in accomplishing these tasks. They are responsible for fostering a warm, supportive atmosphere in which everyone feels equally important. The basic goals of support group members are to offer friendship, support and encouragement to one another, and to gain information. In addition, Parkinson's support groups provide encouragement, reinforcement and support to spouses, caregivers, families or friends.

Contact the facilitator for time and location of support group meetings. For additional information, please contact the Information & Referral Center at 515/241-6379, or toll-free at 877/872-6386, or via e-mail at [erwinjs@ihs.org](mailto:erwinjs@ihs.org).

As Exira closes their books after 10 years of support, we would like to extend a big thank you to Carrie Jensen. In turn we need to welcome Mark Ewing of Cedar Falls, and Jerry Kemperman and Kay Heimes of Boone, as they open their books for the first time this month. Joining us are Dike and Iowa City.

<b>Ames</b> Virginia Dowling 515.239.2605	<b>Clarion</b> Roger Summers 515.532.2507	<b>Des Moines</b> <b>Young Onset</b> Sam Erwin/Denny Neubauer 515.241.6379/	<b>Jefferson</b> Kathy Morain/Linda Smith 515.386.2114
<b>Boone</b> Kay Heimes/ Jerry Kemperman 515.432.2196 515.432.8379	<b>Clinton</b> Don & Rita Schneider 563.332.5071	<b>Dike</b> Bill Hinkle 319.989.2110	<b>Newton</b> John McConeghey 641.791.4639
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<b>Clarinda</b> Marilyn Bousch 712.534.2545		<b>Iowa City</b> Judi Gust 319.351.5248	<b>Waterloo</b> Nancy Hart 319.235.3590
			<b>Austin, MN</b> Ethel Mae Sellers 507.437.4079

### Art - PD Style

Thank you for the many artists who participated in our first Art-PD Style at the Patient and Family Education Seminar on June 30. Artist contact information is available from Denny Neubauer at 515.265.4889 or [dennyknife@yahoo.com](mailto:dennyknife@yahoo.com). Participating artists:

John Baker	Connie Hoogeveen	Denny Neubauer
Bob & Nadene Bryan	Cheryl Hintzche	Jim Polo
Harold Cashman	Jerry Kemperman	Corliss Smalley
Lois Cole	Helen Lorenzen	Deb Wityk



# The Genetics of Parkinson's Disease



Lynn K. Struck, M.D.  
Neurologist with Iowa Health Physicians,  
Medical director of the Information & Referral Center,  
Iowa Methodist Medical Center

Parkinson's disease was noted to have a familial component as early as the 1800s. Recently the discovery of several genetic factors emphasized the importance of heredity in Parkinson's disease. Ninety-five percent of Parkinson's disease is sporadic, and only 5 percent is inherited. Of the genes implicated in familial Parkinson's disease, the largest number of mutations have been found in the "parkin gene," and mutations in this gene may account for Parkinson's disease in as many as 50 percent of familial patients with autosomal-recessive juvenile parkinsonism.

With the identification of genes that are implicated in the causation of Parkinson's disease, it is now possible to ask how this information will impact the many patients diagnosed with this neurodegenerative disease. There are both short-term and long-term implications when answering this question.

In the short term, the direct clinical impact of the identification of these mutations is quite limited. A relatively small number of families have been found with mutations in these genes and, therefore, their discovery is unlikely to have a broad impact on the millions of individuals affected with sporadic Parkinson's disease worldwide.

In the long term, the discovery of these genes is extremely important for understanding the biological pathways altered in Parkinson's disease. The identification of genes resulting in Parkinson's disease has revolutionized the theories underlying disease pathogenesis. In the past, simply understanding the molecules involved in a disease pathogenesis has allowed new therapies to be developed. Thus, even if mutations in alpha-synuclein, parkin, or DJ-1 are not central to Parkinson's disease, the molecules themselves are, and the next generation of PD treatments will no doubt be based on research that would not have been possible without the identification of that first rare mutation in alpha-synuclein.

This is a list of the genes, proteins, and regions implicated in Parkinson's disease. This includes some, but not all, that have been identified.

1. Alpha-synuclein, the first PD-related gene to be identified.
2. Parkin, a gene discovered through studies on rare, juvenile-onset forms of PD.
3. DJ-1 (PARK7), a gene linked to another early-onset form of PD.
4. PINK1 (PARK6), a gene found in several families with PD.
5. DRDN, a gene implicated in the late-onset form of PD.
6. UCH-L1 (PARK5), a gene that is a member of the ubiquitin-proteasome system that helps identify misfolded proteins for breakdown.
7. Synphilin-1, a protein that interacts with alpha-synuclein and promotes the formation of cellular inclusion similar to Lewy bodies.
8. Tau, a protein constitution of microtubulars whose aberrations may contribute to sporadic Parkinson's disease.
9. PACRG, a gene which interacts with parkin, and seems to be part of the protein degradation system and appears to be a component of Lewy bodies.
10. PARK3, PARK9, PARK10, and PARK11, chromosomal regions which have been implicated in Parkinson's disease, but the regions have not been narrowed down to specific genes.
11. GSTO-1 and GSTO-2, genes that appear to play a role in the brain information found in patients with PD.
12. Fibroblast growth factor 2 (FGF2), a gene that helps to maintain neurons which, when mutated, may be a risk factor for PD.
13. Apolipoprotein E, whose genetic variations appear to influence the age of onset for PD as they do for Alzheimer's disease.

## FDA Approved Zelapar® for Parkinson's Disease Patients

Valeant Pharmaceuticals International announced on June 15 that the U.S. Food and Drug Administration (FDA) approved Zelapar® (selegiline HCl) Orally Disintegrating Tablets, a once-daily adjunct therapy for Parkinson's disease patients being treated with levodopa/carbidopa who exhibit deterioration in the quality of their response to this therapy. Zelapar, a monoamine oxidase-B (MAO-B) inhibitor, is the first Parkinson's disease treatment to use a novel oral delivery system called Zydis® Technology, which allows the tablets to dissolve within seconds in the mouth and deliver more active drug at a lower dose.

“With more than 1.5 million Americans with Parkinson's disease, and 60,000 new cases diagnosed each year, having new treatment options available to help manage the symptoms associated with the disease are critical,” said Valeant president and chief executive officer, Timothy C. Tyson. “The approval of Zelapar means that patients now have an additional alternative that can help them significantly reduce their daily “off” time during waking hours. Zelapar is the second therapy Valeant has brought to market to help in the treatment of Parkinson's

disease, and we remain committed to the Parkinson's disease community and to providing therapies that fill the tremendous unmet medical need.”

The use of Zelapar as adjunctive therapy to levodopa/carbidopa has been shown to reduce “off” time, on average, by 2.2 hours per day. Levodopa/carbidopa is commonly used early in the treatment of Parkinson's disease, but as the disease progresses it becomes increasingly difficult to adequately control symptoms with this medication. Parkinson's disease patients may endure many hours of “off” time each day in which their symptoms return as a result of levodopa/carbidopa wearing off.

“Patients with Parkinson's disease still experience many hours a day during which their treatment wears off,” said Cheryl H. Waters, M.D., F.R.C.P. (C), Albert B. and Judith L. Glickman professor, Department of Neurology, Columbia University Medical Center. “The unique formulation of Zelapar allows the orally disintegrating tablet to dissolve within seconds. By delivering more active drug at a lower dose, Zelapar significantly reduces “off” time, giving valuable hours back to the patient.”

***For more information about Zelapar® check with your physician.***

## Exercise Classes for those diagnosed with Parkinson's Disease

These classes are made available with the joint efforts of the Des Moines Area Parkinson's disease support group and APDA Information and Referral Center, Iowa Health-Des Moines.

**Balance Benefit Program** – Improve your health through the *Balance Benefit* program, designed for those with Parkinson's disease or similar conditions who wish to experience a healthier independent lifestyle. The class incorporated stretching, cardiovascular activities, leisure education and strength training in a supportive group environment. **Physician consent and pre-registration is required.** To register contact Cynthia Bowen 643-0473. **Cost:** \$25 for a 5 session class.



**Tai Chi – QiQong.** QiQong comes from two Chinese words: Qi (chi) means energy and Qong (kung) means a skill or a practice. QiQong therefore means a skill or practice of cultivating energy. QiQong can improve your physical and mental health. It provides all the benefit of meditation (reduced stress, lower blood pressure, and better attitude) with physical exercises. The enhancement of the mind/body connection increase your awareness of where your body needs work – where your body needs changes related to diet, exercise, sleep, lifestyle etc. **This class is ongoing. Instructor:** Margaret Gass.

Cost: \$5 per class.

**What should participants wear to class?** Comfortable clothing, such as sweat pants and t-shirts with comfortable shoes, or bring slippers.

**Location of classes:** Mercy Capitol, 603 East 12<sup>th</sup> Street, Des Moines Iowa.

**Questions:** Call 241.6379

## The Grace of Being a Caregiver



Every caregiver experiences a call.

For some, that call comes in the anxious voice of a family member or friend, or with an imploring look in their eyes, either of which says, “I need you.”

For some, the call comes through anonymous faces lined with suffering, both young and old, both near and far. For some, the call is handed from one generation to another, like a trust or from guide to pilgrim, like an honor; or from lover to loved, like a gift.

For some, the call is carried by that Voice from above, that Spirit at their side.

However it comes, the communication is the same: “You are wanted.”

However it’s delivered, the question is implicit: “Will you help?”



*It’s not easy being a caregiver*

There are days when your vitality runs low, when your spirit sags, when your anxiety peaks.

There are times when the hours are too long, when the demands seem too many, when the rewards feel too few.

There may be instances when the other is hard to care for—they may be angry and depressed and take it out on you; they may feel lost or forsaken and push away your efforts to help.

There may be periods when you feel unacknowledged or unappreciated, when you feel lonely and alone.

There may be times when what’s expected of you seems beyond your abilities, when what’s asked of you is more than you have to give.

Being a caregiver has demands and difficulties, annoyances and adversities.

It has its full share of pain.

*Yet being a caregiver can be one of the most meaningful things you’ll ever do.*

You can help a fellow human being as you yourself would want to be helped.

You can do for another what they could not do without you.

You may be able to nurse them back to health and vitality, or you may accompany them to a place of relative calm and stability, or you may witness their journey from life on earth to a life beyond.



But that is only the beginning.

There will be times in your caregiving when you realize, however much the other has gained, you have gained just as much, and perhaps even more.

In the act of accepting, you will be accepted in a way you have not before.

In the act of comforting, you will be unexpectedly comforted.

In the act of dying with another, you will be reborn.

There will be times in your caregiving when, however tired you are, you’re ever so alive; however separate you feel, you’re ever so connected;

Whatever brokenness you’ve known, you’ve never felt more whole.



Those will be the times when you begin to fathom what it means to love.

*Through the discipline of your caregiving, you will experience marvelous new awareness.*

In being a blessing for another, you are blessed.

In being a vehicle for growth, you grow.

In being a conduit for healing, you are

healed.

And, in holding out the promise that, no matter what has happened, transformation is still possible, then you yourself can be transformed.

Caregiver and care receiver alike transform one another.

One of you loves, and one of is loved, and you’re both the same.

And you will know that transformation is not something **you** have accomplished.

It comes from beyond you.

You will realize, if you do not already, that you are cared for on the grandest scale possible.

And the most fitting response you can make is a prayer that contains only four words:

Thank you.

Thank you.

– Adapted from *The Caregiver’s Book, Caring for Another, Caring for Yourself* written by James E. Miller Copyright 1996.

The American Parkinson Disease Association, Inc., was founded in 1961 to "ease the burden and find a cure" for Parkinson disease. Headquartered in New York, the organization focuses its energies on research, patient services, education and raising public awareness of the disease. The APDA national office also coordinates the efforts of chapters and information and referral centers across the nation. In 2004-2005, the APDA budget for research was more than \$2.5 million, plus APDA funded eight advanced centers for PD research. Annually, the APDA scientific Advisory Board reviews grant applications and recommend funding for researchers whose work shows promise for new breakthroughs or improved treatments.

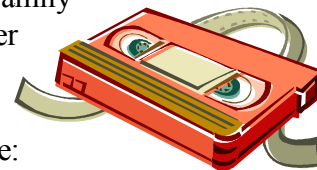
National American Parkinson  
Disease Association  
135 Parkinson Avenue  
Staten Island, NY 10305

## Caregivers' Support Group

All caregivers are invited to come together to discuss the needs you have as a concerned family member at [time] Thursday, Oct. 26, in Hill Auditorium, Iowa Methodist Medical Center. If you would like additional information please call 515.241.6379

## Seminar Video Available

If you were unable to attend the Patient and Family Education Seminar held in June, you can order a copy of the recorded version. Send your request by fax, mail, email or phone to Fax: 515.241.6393; email: [erwinjs@ihs.org](mailto:erwinjs@ihs.org); phone: 515.241.6379 or mail: APDA I & R Center, Iowa Health-Des Moines, 1200 Pleasant Street E-524, Des Moines, IA 50309.



You can make contributions to the Iowa Chapter by sending a check made out to  
Iowa Chapter APDA to APDA, PO Box 507, Waukee, Iowa  
50263.

Your donations are used for the purchase of books and other resources, support for PD support groups, operating expenses for the Iowa chapter and research funded by the national APDA office.



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