



## MISSION

Our mission is to enhance the quality of life for people with Parkinson's disease, their families, and caregivers in the St. Louis area, and to provide funding for ongoing Parkinson's disease research.

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### NEWSLETTER DISCLAIMER

"The information and reference material contained herein concerning research being done in the field of Parkinson's disease and answers to readers' questions are solely for the information of the reader. It should not be used for treatment purposes, rather for discussion with the patient's own physician."

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# LINK STL apda

February 2008; Vol. 21, Issue 1

## WHAT DOESN'T GET SAID OFTEN ENOUGH...THANK YOU!

Deborah Guyer, MA, CCC-SLP



While I was recovering from my Achilles tendon surgery, I took on a new role, that of a patient. Those of you who know me must realize how very difficult it was for me to be dependent on someone else...for what seemed like forever. And while I was playing the patient role, I must tell you how appreciative of my husband I was. He, too, was playing a new role, that of my caregiver. And the thing that sticks out in my mind was how important it became for me to always say thank you to my care providers. And then I thought about how many of the patients I have seen with advancing Parkinson's Disease who may not be able to be heard when they offer their thanks to their care providers. How many of them can't even accurately display the emotions they are feeling because of that mask-like facial expression we have come to know as characteristic of PD. So for the patients and caregivers reading this newsletter, a BIG and LOUD THANK YOU for the job that you do each day. Please do it lovingly, knowing that it is very much appreciated, in spite of the difficulty we patients may have in uttering thank you. I know that as a caregiver, it may make you feel under-appreciated to not hear those words or see that smile, but it is there...and I offer those words and thoughts to you from a new perspective I gained over the holidays. That's why I feel so passionate about being your voice.

More thank yous are due – as we tally donations received since Thanksgiving. We want to express our sincere thanks to the donors you see listed in the tribute section of this newsletter. You can tell by the number of pages, that Sally Koch's thought, "great opportunities to help

others seldom come, but small ones surround us every day," is indeed present in our community.

I want to publicly thank Brandi Koziatek, our new Special Projects Assistant, for stepping up to the plate, and handling the daily operations of the APDA Information & Referral Center in my absence. Brandi is a GREAT addition to our office and I look forward to many of you meeting and working with Brandi.

I have one more THANK YOU that I say from all of us. It is to philanthropist and businessman, Louis S. Sachs, Chairman of Sachs Properties Inc. Mr. Sachs has graciously donated, rent free, a beautiful office space at 1415 Elbridge Payne Road in Chesterfield, as our new satellite resource center. This space will be available for our use for 3 years which will take us through the Highway 40 construction closures. It is our "field of dreams." This Center will enable us to be fully accessible to you, providing a space to meet and talk. Parking is just outside the door and the office is located on the first floor. We will hold some support group and Board meetings there. We will have committee meetings there and have a place to assemble auction baskets. There will be a library filled with books and DVDs to view and a computer marked with favorite websites and volunteers who can help you view information on line. We will stock



Louis S. Sachs, Chairman of Sachs Properties Inc  
continued page 2

**APDA Information & Referral Center**

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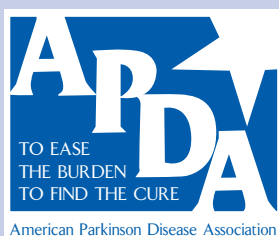
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# THANK YOU CONTINUED FROM PAGE 1

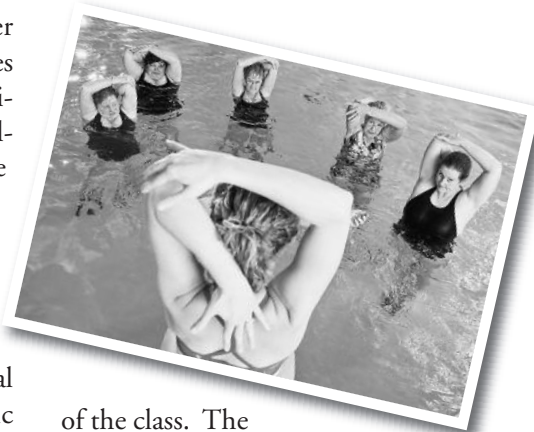
small adaptive equipment, booklets and supplements and we hope to have a telephone “hot line” available for you to call in to chat with trained personnel familiar with PD. This satellite resource center will not supplant the offices that we presently have at Washington University, but will be in addition to and we are

seeking volunteers who may wish to spend time assisting us at this satellite location. We will let you know what our phone number and hours of operation are-so stay tuned! We are extremely grateful that Louis Sachs is adding APDA to his long list of philanthropy.



## A FIRST TIME AQUATIC EXERCISE CLASS BEING OFFERED-LIMITED NUMBER OF SPACES AVAILABLE

Come experience a water exercise class that includes low impact aerobic activities, flexibility, strength, and balance. The St. Louis Chapter of the American Parkinson Disease Association and ShowMe Aquatics and Fitness will be hosting a 10 week class at the Franciscan Sisters of Mary Convent Pool located behind St. Mary’s hospital off Clayton Road. An Aquatic Therapy and Rehabilitation certified instructor will bring the expertise to help you see the benefits



of the class. The class is being held on Wednesdays from 3:30 pm to 4:30 pm beginning April 9, 2008 and ending June 9, 2008. The class will only take a maximum of 10 participants and the registration deadline is **March 7**. To register, please call the APDA Information & Referral Center at 314-362-3299.



**REMEMBER** the St. Louis APDA  
 in your will, trust, life insurance policy,  
 or retirement plan.

# QUESTIONS FOR THE DOCTOR

Lee W. Tempel, M.D.

## 1. As a relatively newly diagnosed patient, how do I know when it's time to be put on medication? I have heard that Sinemet is only effective for so long, so isn't it better to put off starting it for as long as possible?

The time to start treatment is when symptoms become significantly bothersome enough. That may vary from person to person. One patient may be retired and tolerate a certain degree of symptoms while another may still be working and not tolerate the same degree of symptoms because of job demands. Someone may have a position in the public eye and not be able to "afford" even minor symptoms (such as a mild rest tremor) because of the public's (incorrect) assumption that such symptoms make him/her "unfit". In any case, it is important to begin treatment before significant gait or balance symptoms might put the person at risk for a fall. It is important to realize that it is **NOT** true that *Sinemet* is only effective for so long. It always remains effective. As time goes on, the dose needs to be increased but it will always give benefit. However, with time there is a complex interaction of disease progression and need for increase in dose that can lead to accompanying side effects such as dyskinesias (involuntary movements) that may certainly complicate therapy. Currently, though, we have several available medications that can be used in the "best" combination for each individual and potentially minimize unwanted side effects. So we may not start out with *Sinemet* in all patients and are unlikely to just use *Sinemet* alone in most patients. Instead we try to strategically use a combination of medications. There is no one "correct way" to do this. The choice among the medications must be individualized based on the patient's age, general health, other medications, whether there is any accompanying cognitive

impairment present, how severe the PD symptoms are, what the goals of therapy are (what degree of symptom control is desired), tolerance of medication side effects, etc. There is a suggestion in some of the current literature that it may even be better to start therapy earlier rather than later in terms of long term performance and outcome but that is not actually known. It is being looked at in more detail in some current trials. Finally, there are no medications currently available that are proven to be "preventive" or "disease modifying" (able to slow down the progression of the disease), although there are some currently available that may have at least a trend or indication that they may do this. Further trials of those medications are under way and other (? better) medications are under development. Once we have a medication with proven efficacy to slow progression, it will be **very** important to begin it as soon as possible once the diagnosis of PD is made.

## 2. I have been told that PD is not genetic and yet I hear about multiple relatives in families having PD. Is that more of environmental issues playing a role, or do you think there are genetic components?

It is clear that PD is actually not a disease, it is a syndrome. That is, there can be more than one "cause" that leads to the same clinical expression of symptoms. We already know of several specific gene abnormalities that can cause PD. Added all together, they only account for a small percent of the overall number of patients with PD. There are also a few specific environmental factors that are known to increase susceptibility to PD, including manganese toxicity and exposure to certain kinds of pesticides and herbicides. However, in the great majority of patients with PD, there is neither a specific known gene abnormality nor specific environmental

exposure. We think there is a complex interplay of both genetic and environmental factors that appear to trigger or increase susceptibility to PD. Epidemiological studies would generally estimate that if someone has a first degree relative with PD that would about double their baseline risk for PD. Currently, there are about 1 to 1.5 million patients with PD in the US. If we assumed that the population is about 250 million that would increase risk from about 1 (or 1.5) in 250 to about 2 (or 3) in 250. So it sounds like a big increase but it is not and it is nothing like the risk of traditional genetics (1-in-2 risk or 1-in-4 risk if a parent had PD). So there will be some mild increased incidence in families but not a remarkable one unless it is one of the few families with a specific gene abnormality.

## 3. Over the last few years we have seen some innovative new treatments for PD. What role might some of these new treatments take in monotherapy or in adjunctive therapy?

This is a very broad question. I will try to briefly touch on some of the newer treatments for PD. Please note: each medication has a generic and trade name from the very beginning when it is released. The generic name is not capitalized and the trade name is capitalized (and I put it initially in parentheses after the generic name). For several years after a medication is released, only the trade name is actually available but both names still exist! The MonoAmine Oxidase (MAO) inhibitors previously only included selegiline (*Eldepryl*). Recently, much more potent MAO inhibitors have been released. These are rasagiline (*Azilect*) and the Orally Disintegrating Tablet (ODT) of



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## QUESTIONS FOR THE DOCTOR CONTINUED FROM PAGE 3

selegiline (*Zelapar*). Because they are much more potent, they now have mild symptomatic benefit for PD (where selegiline did not). *Azilect* can be used as initial monotherapy. Both *Azilect* and *Zelapar* can be used as adjunctive medication with levodopa. They are both taken once per day. The newest dopamine agonist is rotigotine (*Neupro*) which comes in a patch formulation that is changed daily. It is indicated for initial monotherapy in early PD. It has also been used "off label" (not for the FDA indication) as adjunctive treatment in later PD. It joins the previously used oral tablets of dopamine agonists; pramipexole (*Mirapex*) and ropinirole (*Requip*). Currently, *Neupro* does not go to as strong of a maximum dose as the oral dopamine agonists do. However, it does seem to have less dopamine-associated side effects which can be important for those patients where that is a problem. It also has con-

tinuous 24 hour action. Another dopamine agonist has been available for some time now and is taken as a subcutaneous injection (like insulin shots). It is apomorphine (*Apokyn*). It is used as a "rescue" for more advanced PD patients who suffer with unexpected "sudden offs" or unexpected "wearing off" to get them quickly back "on" again. It takes effect within 10 to 15 minutes and lasts one to one and a half hours (until the next dose of scheduled medication). It is used as needed. Not as new any more, but worth mentioning, are the COMT inhibitors; entacapone (*Comtan*) and tolcapone (*Tasmar*). These must be used as adjunctive therapy with levodopa. They allow a dose of levodopa to have a longer duration of effect and also a mildly stronger effect through that time. *Comtan* is typically taken with each dose of carbidopa/levodopa (*Sinemet*). *Tasmar* is typically taken

three times per day. Entacapone (*Comtan*) is also available already in combination with carbidopa/levodopa (*Sinemet*) in a single tablet and then it is called *Stalevo*. Each *Stalevo* tablet has a "full" dose of entacapone (*Comtan*) but may have the equivalent of one half tablet, one tablet, one and a half tablets or two tablets of *Sinemet* 25/100 in it. The important point to be made is that since there is always a full dose of entacapone, one should **NEVER** take two *Stalevo* tablets at the same time or you will be "double dosing" on the entacapone. For example, do **NOT** take two "*Stalevo* 50" tablets to try to make one "*Stalevo* 100". Of course, extra *Sinemet* **CAN** be added to any tablet of *Stalevo* under the direction of your physician.



## PARKINSON'S PREDICTORS?

*The following article appeared in a recent publication of the Transmitter, the magazine of the Parkinson's program in Victoria, BC. With their permission, I wish to share these opinions of neurologist, Dr. Mandar Jog, Director of the Movement Disorders Program at London Health Sciences Centre which he presented at the S.W. Ontario Regional Parkinson's Conference, in June 2006. Dr. Jog discussed the following non-motor symptoms as potential early indicators of Parkinson's disease. The editor does remind the readers that if you experience any of them, consult with your physician for treatment, as they may be related to your Parkinson's disease.*

**Smell Dysfunction (Hyposmia)** is a reduced ability to smell. 70-100% of people living with PD report having loss of smell. 20-30% of first-degree relatives (e.g. parents or siblings) of those with Parkinson's also admit to having symptoms of hyposmia. By studying the brain, scientists have discovered the presence of Lewy bodies in the olfactory system (region of the brain controlling smell) before they are found in the substantia nigra, where dopamine is produced.

**Constipation** – According to recent study results, people who had one or less than one bowel movement per day had

the highest incidence rate of Parkinson's. Lewy bodies (clumps of protein found in the brains of people with PD,) also seem to be present in the part of the brain that controls bowel function.

**REM Sleep Behavior Disorder (RBD)** is a condition in which people seem to "act out" the dreams they have during a stage of REM (Rapid Eye Movement) sleep (e.g., flinging of arms, screaming, kicking, etc.)

**Restless Leg Syndrome (RLS)** is an unusual sensation in the legs (i.e., insects crawling) that cause an uncontrollable desire to move them when at rest in an effort to relieve these feelings. This con-

dition usually responds well to dopamine therapy and can pre-date a diagnosis of PD by as much as 10 years.

Since Dr. Jog's presentation, a long-term study has been initiated in Connecticut involving PD and the sense of smell. If neurologists are able to predict who may be at increased risk for developing Parkinson's, perhaps, ultimately, it can be prevented before it starts. Many of you will recall that Dr. Perlmutter reported that at the time of diagnosis, sometimes there is already an 80% loss of dopamine.

If clues to Parkinson's disease may appear long before diagnosis, then iden-

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## PARKINSON PREDICTORS CONTINUED FROM PAGE 4

tifying people who will develop PD early enough may provide a window of opportunity to intervene early and arrest the development of PD. You will recall that there are no blood or laboratory tests to diagnose PD. However, frequently patients look back after the diagnosis has been made and realize that they had lost their smell discrimination ability. Some people report having acted out their dreams for years (REM Behavior Disorder) and half of them develop Parkinson's disease or some other degenerative disease of the brain from three to ten years after being diagnosed with REM Behavior Disorder according to

Dr. Kapil Sethi from the Medical College of Georgia. Dr. Sethi feels that intervening early may give a patient three extra years up front, which is much more important than trying to prolong patient's lives in the end for three more years. "Because the quality of life is never going to be the same, it's better to delay the onset of PD." Research is underway across the country to determine who is at risk for developing Parkinson's disease and these possible predictors may enable physicians to delay or slow the condition's onset in the near future.

*(Dr. Joel Perlmutter offers this commentary on the article you have just read: The only caveat that I have is that these methods have not yet been proven to have specific efficacy – that is we do not yet know how specific these findings are. In fact, it is very likely that there are many people with small difficulties that will not go on to develop PD. Additionally, there is no evidence that treating anyone before they get PD will help to slow disease progression. Hopefully this will be true in the future, but not yet. That is the great hope of these types of studies – to find an early sign of PD that will permit early treatment, once it becomes available, to forestall the onset of PD symptoms.)*

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## ENVIRONMENTAL RISK FACTORS AND PARKINSON'S DISEASE

By A. W. Willis, M.D., Movement Disorders Center

Department of Neurology, Washington University School of Medicine

*Dr. Willis is a Clinical Instructor/Fellow at the Movement Disorders Center at Washington University School of Medicine. Her research focuses on environmental risk factors for Parkinson Disease and conjugal PD (cases in which two married or cohabitating people both develop Parkinson Disease.)*

**P**arkinson's disease (PD) is a relatively common neurodegenerative disease of the elderly which affects 1% of the population greater than 65. PD was originally thought to be largely due to genetic mutation, a belief supported by the fact that many patients with parkinsonism report a relative with a PD like movement disorder. Genetic research has identified a number of rare familial forms of PD that are inherited. However, the cause of greater than 90% of cases of PD is not likely to be explained by a single gene mutation. Studies suggest that environmental factors play a major role in the development of PD.

The discovery that PD has an environmental rather than genetic basis has led to great interest in identifying toxins which may be associated with PD. The environmental risk factors most frequently associated with PD in studies are rural habitat, industrial habitat, pesticide use and heavy metal exposure. However, the cause of PD is still under investigation, with age

being the only clear risk factor.

An increased risk of PD has been reported in people who live in rural, urban, and industrial areas of the U.S. While this information seems conflicting, there may be different risk factors in each habitat which are associated with a greater risk of PD. In studies of rural areas, exposure to insecticides, herbicides (weed killing chemicals,) or other pesticides were suspected to be the culprit. Other researchers have studied exposure to well water found in rural areas, as opposed to municipal water sources. The results of these studies are conflicting- some report an increased risk of PD in those living in a rural area or drinking well water, others have not found such a relationship.

There are many studies on pesticide use and the risk of Parkinson's disease. Pesticides have been reported to cause a syndrome of slowness, shaking, and difficulty walking that resembles PD with high amounts of exposure. Parkinson's

disease has been reported to be more common among farmers, pesticide applicators and others who work in the agricultural sector. However, little is known about the average person's risk of PD from infrequent pesticide use that occurs from recreational gardening or landscaping. Current research is studying how much pesticide exposure is associated with PD, and if people living in areas of the country where a lot of pesticides are used are more likely to be diagnosed with PD. There are also studies of PD risk involving people who work with large quantities of pesticides frequently over many years. Currently there is no evidence that consuming lots of fruits or vegetables that have been treated with pesticides increases your risk of PD, so be sure to eat well!

In addition to studying the risk of PD that may be related to rural living, farming, or pesticide use, researchers have also investigated the risk of PD in people living in urban or industrial areas. An increased risk of PD has been reported

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## ENVIRONMENTAL RISKS CONTINUED FROM PAGE 5

among people in these areas, and is thought to be secondary to heavy metal exposure. Heavy metals are a special group of the elements, and are found everywhere in nature. Examples of heavy metals include aluminum, copper, manganese, zinc, iron, mercury, and lead. Heavy metals are not all bad- some heavy metals (such as iron) are vital to our existence. Iron is an integral component of hemoglobin, the molecule which carries oxygen in red blood cells. Other heavy metals vital to human bodies for function include zinc, copper, and manganese.

However, as with pesticides, research has shown that exposure to large amounts of certain heavy metals can also produce symptoms that resemble PD. These effects of heavy metal exposure have been observed in people who work with certain metals, who may be at an increased risk of PD. This area of PD research is also very exciting, with current studies examining the storage of heavy metals in blood or the brain and risk of PD, and the risk of PD in regions of the country with high natural or secondary environmental heavy metal concentration or exposure.

In summary, there are many environmental factors which are suspected to increase the risk of Parkinson's Disease, including living in a rural, urban, or industrial habitat, pesticide or heavy metal exposure. However, no study has conclusively associated any environmental agent with PD. More research is needed before any of the proposed risk factors can be linked with Parkinson's Disease. The results of current studies may clarify the risk of PD attributable to these and other environmental factors.



## LIBRARY HIGHLIGHTS

### Making the Connection Between Brain and Behavior-Coping With Parkinson's Disease book review

Dr. Joseph Friedman's recently published book, Making the Connection Between Brain and Behavior – Coping with Parkinson's Disease is a good read! When people think about Parkinson's disease they usually picture tremor, shuffling, and other physical changes. And yet Parkinson's Disease (PD) is not only a movement disorder. It is estimated that 65-90% of PD patients experience some level of depression, anxiety, dementia, hallucinations, paranoid delusions, sleep disorders and other behavioral disorders that affect everyone involved. Nearly 50% of persons with Parkinson's (PWP) suffer from depression. The depression is part of the illness, not simply a reaction to the disease. Dr. Friedman points out that depression is a symptom that is often under-diagnosed secondary to the loss of facial expression, sleep disorders, fatigue and communication problems that plague the individual with this chronic illness. This book focuses entirely on the behavioral changes associated with PD that create the most stressful problems for loved ones and family members, much more so than the motor problems.

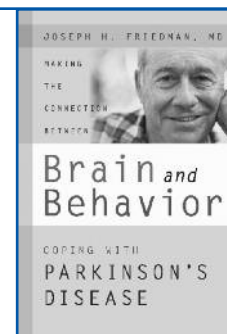
Dr. Friedman uses vignettes to illustrate common behavioral problems PD

patients experience and present with, throughout the book. His writing is straightforward and easy for even the layperson to understand. I found it interesting, but not surprising, to learn that about half of the people with PD report that fatigue is one of their three biggest problems, and one-third report that fatigue is their single worst problem, and yet it tends to be under-recognized and undertreated.

PWP are high-anxiety people. Dr. Friedman describes the belief some hold that this is a "personality trait" that leads to the development of PD. Up to 40% of PWP experience anxiety in the form of generalized anxiety, obsessive-compulsive disorder and social avoidance. Dr. Friedman points out that facial masking with loss of expression, sleep disorders, fatigue, inability to initiate activity, hallucinations and decreased communication symptoms are symptoms of both PD and depression that may be overlooked.

Cognitive changes are present in more than 50% of PWP, and in late-stage PD this number may be even higher. Although about 30% of PWP have some dementia, a majority of people with this

chronic disease have mild cognitive impairment that does not significantly alter how they lead their lives. You may recall that Dr. Burack explained that many PWP complain of a slowness of thinking and difficulty with word finding. Problems are exacerbated during "off" times and will lead to social withdrawal. Dr. Friedman notes that, "Even the difficulty of engaging in conversation when it's difficult for people to hear what the PD patient is saying dramatically reduced the enjoyment the social gatherings once brought." I have witnessed many PD patients losing their motivation and interest, and being described by their caregivers as "not caring." Read Dr. Friedman's article on apathy in this newsletter which will give you a whole new perspective, I hope. You will find yourselves nodding in agreement and realizing that what you once assumed was lack of motivation may be fatigue or depression or apathy, all common traits and not fully understood or treated in patients with Parkinson's disease.



# TRIBUTES

## Honoring

### Special Birthday

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Celeste Dillon

#### *Arthur Blatt*

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#### *Michael Bruckdorfer*

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## APATHY

By Joseph H. Friedman, MD

*Dr. Friedman is the Director of the Parkinson's Disease and Movement Disorders Center of NeuroHealth; Clinical Professor of Clinical Neurosciences at the Warren Alpert School of Medicine of Brown University; and Adjunct Professor in the School of Pharmacy of the University of Rhode Island. Dr. Friedman is the author of the 2008 book, Making the Connection Between Brain and Behavior-Coping with Parkinson's Disease (which is reviewed on page 6 of this newsletter.)*



The word apathy means indifference, not caring, lack of interest. It is not necessarily a problem. We all have areas of interest and areas where we lack interest. Some people like classical music and others are indifferent to it. They don't care about it. They are apathetic as far as classical music is concerned but they may like jazz or hip hop or some other type of music. Some people don't like music at all.

Apathy is a problem when it has a negative effect on someone's life. In the setting of Parkinson's disease, it represents a change in personality and it is common. Despite its frequency, it is

poorly understood, under-recognized and unappreciated by most physicians.

Apathy, to some degree, affects about 40% of PD patients. They are less interested in things in general than they used to be. They are less motivated. They are less likely to think up new and interesting things to do, and are less likely to want to join activities that are outside of their usual pattern of behavior. In PD the most obvious examples can be seen in the person who used to be talkative and social who increasingly stops interacting, talks less and less and withdraws more and more. Usually it begins with some good reason, like a speech prob-

lem. The person has a soft voice and his friends and relatives are a bit hard of hearing so they can't hear him. He gets tired of repeating everything two or three times so he tends to talk less. After a while he barely talks, then he loses interest and starts to fall asleep during the conversations since he's never involved. However, this may not be the whole story. It is unfortunately common for PD patients to become almost mute, except when directly asked a question. I often have patients in my office who don't say anything unless I talk to them directly. "How are you doing?" and the

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## APATHY CONTINUED FROM PAGE 11

spouse or child answers, "She's pretty stable." If I ask the patient the question directly, I almost always get an answer, yet the patient will not volunteer anything and will wait for someone else to answer.

Many PD patients simply lose interest in whatever is going on around them. It's a slow process and never develops suddenly, although the family may suddenly notice it. Over time they start watching TV increasingly, explaining that it's "too hard" to go shopping, visit a friend, or go for a walk. It's easier to sit and be passive. Sometimes the apathy reaches a point where it may not even matter if the TV is on or off. It's almost like the movie, *Invasion of the Body Snatchers*. The "spark" of life is dimmer. And while this can be very difficult for the family, the patient actually isn't suffering. When I ask an apathetic patient if he's depressed or sad, the answer will be, "No." On the other hand, the patient doesn't feel happy

either, or excited or angry or irritated or anything. The apathetic person doesn't look forward to much, doesn't enjoy much, but doesn't suffer either. I often reassure the family that the patient is apathetic. He doesn't care. The family cares and thus the family suffers more than the patient. In some cases this may even seem protective for the patient. He's not suffering. He doesn't care that he can't walk, or be understood. It no longer matters.

It can be difficult to distinguish apathy from depression. They look the same. The real difference is that the depressed patient is sad, or irritable, may seem angry and negative, or may lose weight, whereas the apathetic patient is very even keeled. No pain. No anger. No irritability. No emotions. The one universal enjoyment I've found however is the visit from the grandchildren. That always raises a smile and is one source of pleasure that even the most apathetic have, but it only lasts a

few minutes before it's over. A brief flame.

Apathy is often, but not always associated with dementia. It can be seen in people who are depressed. It may be difficult to distinguish from fatigue.

No one knows how to treat apathy. The usual medications for PD have no effect nor do antidepressants or stimulants. And I'm not sure that it would always be a good thing to treat if we did know how to treat it. Sometimes it may be better to not care. Insight isn't always a good thing to have.

I find that it can be difficult to determine if the patient is apathetic or depressed. When I'm unsure I recommend a trial of an antidepressant since depression is worth treating. Depressed people are suffering whereas apathy causes suffering in those who love the patient but not the patient.



## WHEN IT ISN'T REALLY HAPPENING

By Kevin J. Black, M.D.

Associate Professor of Psychiatry, Neurology, Radiology and Neurobiology  
 Washington University School of Medicine

**G**randpa sees people at the dinner table who aren't really there. What is going on?

A substantial minority of people with PD develop psychosis at some point in their illness, and it is an important problem. Let me first define terms so we are all talking about the same thing. The word psychotic has a very specific meaning to doctors. It does not mean what your teenager or the man on the street means by it. There are 4 kinds of psychosis but only 2 tend to occur in PD: hallucinations and delusions. A hallucination is a sensory percept of something that isn't really there. Any of the senses can be affected. One could hear or see or even smell something that is not there,

and all those experiences are called hallucinations. In PD the most common hallucinations are brief and visual, like seeing extra guests at dinner or bugs on the wall, but all kinds of hallucinations can happen in PD. By contrast, an illusion is when you really do see (or hear) something real, but you think it is something else until you see it better. The classic example is seeing an intruder in your bedroom until you figure out it is just your bathrobe hung over the door. Doctors do not classify illusions as indicating psychosis. A delusion is different. A delusion is a fixed, false belief that the people around you don't share. An example could be the belief that people are spying on you, or that your spouse is

unfaithful, or that people are stealing from you. These are all things that could happen, so sometimes it doesn't become clear that they are delusions until after some fact checking. Bizarre delusions, like thinking that aliens implanted a camera in your left eye, don't occur very often in PD.

There are several things that can cause psychosis in PD. Here are some of them.

If psychosis comes on in a short period of time, when someone is also quite confused, it may indicate delirium. When I



## WHEN IT ISN'T REALLY HAPPENING CONTINUED FROM PAGE 12

say confused I mean things like not knowing the date or what's going on. Delirium is also known as "acute encephalopathy" or "mental status changes." It is usually caused by serious physical illness or medication side effects, e.g. when someone has a heart attack or an operation, or starts a new medicine. Since it happens so often in intensive care units it is sometimes called "ICU psychosis." Patients with delirium often have good and bad moments during the course of the day, and often are more confused at night. They may fall asleep frequently in the day or be up at night. I think of delirium as "acute brain failure." It means that something is very wrong physically. Sometimes what's wrong is obvious (like when you are in the hospital for pneumonia or just started certain medicines,) but when it isn't obvious, a doctor should evaluate the patient with a review of recent symptoms and medications, a physical exam, and maybe some blood tests or an EKG depending on the details. The good news about delirium is that it usually goes away if the underlying illness gets better. There are medications that help too and they may need to be given only temporarily.

If psychosis develops more gradually, and starts before or soon after the physical signs of parkinsonism appear, it is possible that rather than typical PD the patient has an illness called diffuse Lewy body disease (DLBD for short, or sometimes just LBD.) Often in DLBD the person manifests marked variation over the course of the day in how sharp they are mentally. Often memory loss or changes in personality will develop over the next few years. Certain medications may help with the psychotic symptoms in DLBD (cholinesterase inhibitors or atypical antipsychotics.)

The more common situation is that someone with PD who was doing OK for 5 or 10 years develops hallucinations

a few weeks after their medication dose is raised. Occasionally hallucinations are rare and don't bother the patient, and sometimes watchful waiting is the best management. However, psychosis in PD often is a big concern to the patient or caregiver. Often it gets worse with time, and psychosis is the biggest reason for nursing home placement in PD. For these reasons I almost always recommend some form of treatment.

Cutting back on the medicine may help, but the dose was probably increased to treat falls or difficulty moving or whatnot, so usually that is a temporary solution at best. Generally we follow the following stepwise strategy in these cases until something works. (1) Check for new physical illnesses or new medications. (2) Stop any medications that commonly add to confusion even in people without PD. There are many of these; common examples are benztropine, trihexiphenidyl, and amitriptyline. A doctor should supervise this since some medications (like alprazolam) can cause problems if stopped abruptly. (3) Simplify brain-active medications if possible. (4) Switch off of dopamine agonists in favor of good old levodopa/carbidopa. At equally effective doses it is less likely to cause psychosis. (5) Many patients may consider enrolling in a clinical trial assessing an investigational drug that may help with psychosis in PD. (6) Consider trying quetiapine (Seroquel®). Increasing evidence suggests it probably doesn't work in most people, but when it does that's

great. (7) Switch to clozapine. Clozapine is a hassle but it is proven to work. It involves getting blood draws every week or two as long as you are on it. (8) Consider a cholinesterase inhibitor like rivastigmine, galantamine or donepezil. (9) Certain other medications have been tried, including ondansetron, and in some patients electroconvulsive therapy (ECT) can help.

Sometimes hospitalization is necessary if someone has psychotic symptoms that lead them to act in dangerous ways, like buying a gun to protect themselves against the people spying on them who aren't really there. In this event, make sure both a neurologist and a psychiatrist are involved and talk to each other frequently. These hospitalizations are usually frustrating to everyone involved but are important as they may save a life. Overall, one or another treatment will work for most people with PD and psychosis.

One piece of very good news is that the National Institutes of Health, the Movement Disorders Society, the Michael J. Fox Foundation, and the APDA are all increasingly aware of how serious psychosis in PD can be and are devoting resources to encourage new research. There are a number of good leads for investigating what causes psychosis in PD and how to treat it. I am quite hopeful for the future.

### DON'T FORGET eScrip!

Every time you shop at Schnucks give your escip card to the checker to record your purchase amount prior to paying for your groceries. If you do not have an escrip card, call the Center (314-362-3299) and request a Schnucks' eScrip community card. When you receive your card you may activate it yourself by calling 1-800-931-6258.

# SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

Our Support Groups meet once a month or as noted.

City	County	Meeting Site	Day of Meeting	Time	Leader	Phone
Missouri						
Cape Girardeau	Cape Girardeau	St. Francis Med. Ctr. 211 St. Francis Dr. SFMC Cafeteria	4th Monday	6:30 pm	Desma Reno, RN, MSN	573-331-5871
Columbia	Boone	Columbia Senior Ctr. 1121 Business Loop 70E Senior Center, 2nd Fl.	1st Thursday	4:00 pm	Gerry Neely, RN	573-815-3554
Creve Coeur	St. Louis	Shaare Emeth Congregation 11645 Ladue Rd.	1st Wednesday	2:30 pm	Lisa Ackerman	314-725-1888
Festus/Crystal City	Jefferson	Disability Resource Association 420 B S. Truman Blvd.	3rd Tuesday	1:00 pm	Nancy Pope	636-931-7696
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 am	Julie Berthold Kim Liefer	314-355-6100
Hannibal	Marion	APEX Rehabilitation Ctr. 115 N. 3rd	1st Tuesday	1:00 pm	Lori Griffith	573-221-1711
Jefferson City	Cole	Capital Regional Medical Ctr. SW Campus, Cafeteria	3rd Wednesday	3:30 pm	Sheryl Toole- Bowles, CTRS	573-632-5384
Joplin	Jasper	St. Johns Regional Medical Ctr. 2727 McClelland	Mondays	1:30 pm	Nancy Dunaway	417-659-6544
Kirkwood	St. Louis	Kirkwood United Methodist 201 W. Adams	1st Monday	7:00 pm	Terri Hosto MSW, LCSW	314-286-2418
Kirkwood/ Oakland	St. Louis	Bethesda Dillworth 9645 Big Bend	3rd Friday	10:00 am	Stacy Pepper, BSW	314-446-2184
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 pm	Maureen Neusel	314-372-2369
Lake Ozark	Camden	Lake Ozark Christian Church	3rd Thursday	5:30 pm	Patsy Dalton	573-964-6534
Rolla	Phelps	Christ Church Episcopal	4th Thursday	10:00 am	Carolyn Tilford	573-364-8899 #6642
Sedalia	Pettis	First Christian Church (Disciples of Christ) 2005 Limit	3rd Monday	4:00 pm	Barbara Schulz	660-826-6039
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 am	Jack Strosnider	314-846-5919
St. Peters	St. Charles	1st Baptist Church of Harvester 4075 Hwy. 94 S.	1st Tuesday	1:00 pm	Ann Ritter	636-926-3722
Ste. Genevieve	Ste. Genevieve	Riverview at the Park 21997 White Sands Rd. Dining Room	2nd Wednesday	10:00 am	Jean Grifford	573-543-2162
St. Louis	St. Louis	<b>DBS Patients</b> Sunrise on Clayton Sr. Living 7920 Clayton Rd.	3rd Thursday	1:00 pm	Stanley Wilensky	314-997-5114
St. Louis	St. Louis	<b>Newly Diagnosed</b> St. Lukes Hospital 232 S. Woods Mill Rd. Conference Room #6	1st Tuesday	10:00 am	Carol Feuerhahn	314-362-3299

# SUPPORT GROUP/EXERCISE CLASS CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

Our Support Groups meet once a month or as noted.

City	County	Meeting Site	Day of Meeting	Time	Leader	Phone
Illinois						
Alton	Madison	Eunice C. Smith Home 1251 College Downstairs Conference Room	1st Monday	2:00 pm	Cheryl Paradine	618-463-7334
Belleville	St. Clair	Belleville Area College Programs & Services for Older Persons 201 N. Church St., Rm. 106	2nd Monday	1:30 pm	Mary Frierdich & Jodi Gardner	618-234-2120, #1156 618-234-4410, #7033
Breese/Carlyle	Clinton	St. Joseph Hospital 9515 Holy Cross Lane	2nd Monday	7:00 pm	Carol, Jessi, or Jim Loepker	618-594-3780
Carmi	White	First Christian Church 504 Bohlever Dr.	3rd Tuesday	1:00 pm	Carolyn Chastain	618-382-4932
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 pm	Bob & Charlotte Kiriakos	618-549-3360
Decatur	Macon	St. Paul's Lutheran Church 352 W. Wood St.	3rd Thursday	1:30 pm	Cathy Watts	217-428-7716
Granite City	Madison	St. John's United Church of Christ 2901 Nameoki	1st Thursday	1:30 pm	Hilda Few	618-797-0527
Greenville	Bond	Greenville Regional Hospital 200 Healthcare Dr. Edu. Dept., Edu. Classroom	2nd Monday	1:00 pm	Lisa Ketchem, RN	618-664-0808, ext. 3555
Mattoon	Coles	Sarah Busch Hospital 500 Health Center Dr.	Last Tuesday starting in April	1:00 pm	Kay McDade	217-258-4040
Mt. Vernon	Jefferson	Greentree of Mt. Vernon, 2nd Floor	4th Thursday	6:30 pm	Donna & Bill Peacock	618-242-4492
Quincy	Adams	Fellowship Hall of Salem Evangelical Church of Christ 9th & State	3rd Thursday	12:00 pm	Barb Robertson	217-228-9318
Springfield	Sangamon	Christ the King Parish Ctr. 1930 Brentwood Dr.	ONLY March 16, May 18, July 20, Sept. 21, Nov.16	2:00 pm	Dan Vonberg	217-546-2125

## Exercise Classes

Our Exercise Classes meet once a week or otherwise noted.  
\*\$20.00/month for Friday's class\*

Clayton	St. Louis	Barnes Extended Care 401 Corporate Park Dr.	Wednesday & *Friday*	1:30 pm	Melissa Lyles, OT	314-289-4253
Chesterfield	St. Louis	St. John's Mercy Rehabilitation Hospital 14561 N. Outer 40	Wednesday	1:00 pm	Debra Luetkemeyer	314-881-4200
South St. Louis County	St. Louis	Garden Villas South 13457 Tessson Ferry Rd.	Monday	11:30 am	Melissa Lyles, OT	314-289-4253
St. Peters	St. Charles	Barnes-Jewish St. Peters Hosp. Ste. 117	Every Tuesday except 1st Tuesday	11:00 am	Holly Evans	636-916-9650
North St. Louis County	St. Louis	Garden Villas North 4505 Parker Rd.	TBA	TBA	Julie Berthold Kim Liefer	314-355-6100

# SAVE THE DATES!



The following programs and events have been scheduled for 2008. Please mark your calendars-you will be receiving additional information in coming months. If you have not received a flyer or invitation within 30 days of the event, please call the Center or check our website [www.stlapda.org](http://www.stlapda.org) for further details.

**Sunday, April 6th** – Dr. Samer Tabbal will present a lecture on Deep Brain Stimulation (DBS): Indications and contraindications for patient selection, description of DBS surgery, description of DBS programming and outcomes of DBS. Dr. Lee Tempel will join Dr. Tabbal following the presentation for a panel discussion and for answering questions from the audience. This meeting will take place at Congregation Shaare Emeth at Ladue/Ballas Roads at 2:00 PM.

**Monday, May 19th** – 10th Annual Nat Dubman Memorial Golf Classic at Lake Forest Country Club, starting at 11:00 am with registration and a buffet lunch and concluding with awards and a prime rib dinner and auction.

**Sunday, July 13th** – Delay the Disease author David Zid and Jackie Russell will join Dr. Lee Tempel for a program dealing with Exercise and Parkinson's Disease. The new book, Delay the Disease –Exercise & Parkinson's Disease and the companion DVD will be available for purchase at a discounted rate. Wear your exercise outfits, as David will take the audience through some of his new group exercise class routines following the lecture. Teva Neuroscience is providing an educational grant to enable us to bring this program to St.Louis.

**Monday, October 13th** – 13th Annual Luncheon, Celebrity Fashion Show and Silent Auction will be held at a new venue: the Sheraton Westport Chalet beginning at 11:00 am.



## MEDICAL WEST HEALTHCARE CENTER SUPPORTS APDA EQUIPMENT FUND-A MEANINGFUL GIFT FOR THE HOLIDAYS

As the holiday season approached back in 2002, the employees of Medical West Healthcare Center started to think about what gift to get the owners, the Sandler family, for the holidays. What gift would truly bring meaning? And then it happened-the thought of honoring the Sandler family by establishing a fund to honor Sylvan and Ruth, and their children, Dayle, Jeff and Ken by contributing the monies collected to the newly established APDA Medical West Equipment Fund. This past year (2007) marked the 6th consecutive year for collecting and donating to this special fund. This year the employees presented a check in the amount of \$ 2015. When the APDA Board of Directors entertained the idea of creating a special fund designated for equipment in conjunction with Medical West Healthcare employees desire to honor the Sandler family, it fit perfectly. We are hoping that there are other businesses or corporations who may wish to honor someone special in their organization who has Parkinson's Disease, and will be encouraged to do so, in light of the growing success of this Medical West Equipment Fund which today is nearing \$ 10,000. Our thanks to the employees of Medical West Healthcare Center for your kind and very meaningful donation.

Washington University School of Medicine  
American Parkinson Disease Association  
Campus Box 8111  
660 S. Euclid Ave.  
St. Louis, MO 63110

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