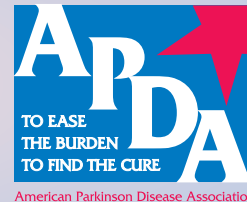


Parkinson's @ Us

Newsletter

Fall/Winter 2008



A Publication of the Georgia Chapter, American Parkinson Disease Association, Inc. and The Information & Referral Center at Emory University

Disease Modification in Parkinson's Disease

By Holy Shill, MD

One of the currently available drugs to treat Parkinson's disease (PD), rasagiline, has recently been studied in a large disease modification trial termed ADAGIO and the sponsoring company (Teva Neuroscience) has just released the positive results. This article will review the concepts of disease modification as it relates to PD, so that patients and families may better understand what these types of results mean.

The first, and probably most easily understood concept of disease modification, is that of neuroprotection. True neuroprotection would be a reduction in the rate of loss of neurons, most specifically dopamine neurons, in the brain. However, this has proved difficult to assess. We obviously do not routinely biopsy the brain with PD to count dopamine neurons, this is simply too dangerous. So, to do a study looking at dopamine cell counts, one would need to follow patients until death, with and without the experimental treatment and then compare cell counts in the brain at autopsy. This type of study is basically impossible; it would take hundreds of patients followed over decades. One can use a surrogate marker of dopamine neurons and this has been done in several large studies. It is possible to label dopamine neurons with a tracer that then shows up on PET or SPECT imaging (similar to a cardiac stress test). These types of studies were done using ropinirole and pramipexole. Both studies showed that these drugs seemed to slow progression on imaging, however, the patients in the study seemed to have more clinical progression of their symptoms overall so that there was a disconnect between how the patients did on their day to day function and the results of the imaging. This has lead researchers to question the validity of these imaging studies.

A second way to look at disease modification is to look at certain clinically important milestones. This would include serious things like death, nursing home placement and needing a walker or wheelchair. But, because PD is relatively slowly progressive, using these types of endpoints for trials would take a long time. Despite this, the FOUND study (coordinated through the Parkinson's Study Group) is

attempting to do this type of study through the use of mailed questionnaires and phone calls after a patient finishes a therapeutic study. Other things that can be more easily looked at are clinical features such needing to start treatment in early Parkinson's. Not everybody needs to be treated right away with PD and so if a therapy slows that need to be treated by keeping people stable for longer periods of time compared with a placebo, one can presume that it is demonstrating disease modification. These types of studies have been done with selegiline, vitamin E and the PRECEPT study drug. Unfortunately, none of these therapies have proved to have meaningful benefits. Minocycline and creatine have been studied along these lines in a type of study called a futility design which basically allows for a study to be done in a shorter time frame and/or with fewer patients in order to screen out those drugs which might not be worth pursuing (futile). Both drugs were "not futile" and creatine is now being studied in a large study in early PD to see if it really works. We are just now starting a large study in coenzyme Q10 which has this type of trial design. Another endpoint that has been looked at is the delay to motor complications, including wearing off and dyskinesia (involuntary movements). It is known that if levodopa (Sinemet) alone is used to treat PD, then most patients begin to have wearing off and dyskinesia within a few years. These motor complications are disabling in and of themselves and therefore, delaying them is important. Ropinirole and pramipexole have been studied along these lines and are shown to reduce these types of complications.

Another way to look at PD progression is to simply look at the rate of disability progression in patients' activities of daily living. However, there is a major confound in looking at this which is that most of the drugs we use to treat PD have what is called a "symptomatic benefit". This means that the drugs have a relatively potent effect in the short term which reduces symptoms and can mask underlying progression. An innovative way to get around this is to do a "delayed start" study. This means that some of the patients get started on the active drug immediately and some get started on placebo. Later, the placebo group is switched to active such that

Continued on page 7

President's Corner

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We are GROWING! Our outreach programs and fundraising successes continue to increase.

Do you know about our Caregiver Time-Out Programs? If you want more information, call Mary Louise Weeks, the Information & Referral Coordinator, at 404-728-6552. We have been able to increase our support for these programs through our successful fundraisers.

And find out more about our ever expanding list of support groups! If you are not already in one of these wonderful fellowship opportunities, again – call Mary Louise!

The attendance at our educational meetings is growing too. Please come and see for yourself. Our speakers are experts in the field and you will have time for questions and answers after the presentation.

Of course, these things could not happen without the efforts of all our fine volunteers who put on the various fundraising activities. Please continue to be generous with your time and donations.

It is wonderful to see the fruits of our hard labor: thanks to all of you for the support and participation in APDA Georgia Chapter events and fundraisers.

Remember that we are available for your questions and comments: My cell number is 404-290-9596 and the "hotline" is 404-325-2020.

Best wishes,
Annemarie Schwarzkopf
President
Board of Directors
APDA Georgia Chapter
www.apdageorgia.org

Best wishes,

Annemarie Schwarzkopf
President
Board of Directors
APDA Georgia Chapter



The Information and Referral Center Needs You!

The I&R Center is seeking volunteers to assist with the monthly educational meetings as well as small projects. If you are interested in donating some of your time to a worthy cause, please contact Mary Louise at 404-728-6552.

Resources for Obtaining Free or Discounted Medications

There are various resources available to obtain free or discounted medications, either through pharmaceutical assistance programs (PAP) or other programs that will do the leg work for you. Pharmaceutical companies offer free assistance to individuals meeting their annual income criteria and have no insurance coverage. If your income is over the required amount they will provide the medication at a discounted price anywhere from 20-40 % depending on the drug.

Listed below are the Parkinson Disease drugs that are available through the drug manufacturers Pharmaceutical Assistance Program. Information and applications can be obtained by calling the phone numbers provided:

Medication	Pharmaceutical Company	Phone
Comtan	Novartis	1 800 277-2254 option 2
Parlodel		
Stalevo		
Mirapex	Boehringer Ingelheim	1 800 556-8317
	Pfizer	1 800 459-4156
Permax	Amarin	1 866 262-7468
Requip	GlaxoSmithKline	1 866 728-4368
Sinemet	BristolMyersSquibb	1 800 736-0003
Symmetrel	Endo Laboratories	1 800 319-4032
Tasmar	Roche Laboratories	1 800 285-4484

Eight pharmaceutical companies have joined TogetherRx, which is a pharmaceutical company assistance program that can save you 20 to 40% on a prescription. The TogetherRx card is accepted by participating pharmacies. To qualify for the card you must meet a certain criteria: (1 are enrolled in Medicare, (2 have an annual income of less than \$28,000 for singles or \$ 38,000 for couples and (3 do not have a prescription drug coverage plan. For more information or to enroll call 1 800 865-7211 or visit the internet website at www.togetherrxaccess.com.

Pharmaceutical Companies offering their own prescription cards are: GlaxoSmithKline Orange Card at 1 888 672-6436 Pfizer for Living Share Card at 1 800 717-6005 or pfizerforliving.com Novartis Care Card at 1 800 865-7211 or careplan.novartis.com

Other pharmaceutical assistance programs available provide information, application instructions, and the required criteria necessary to obtain free or discounted

medications. They will process the application forms with the pharmaceutical company for you. There may be a one-time fee charged for this service. For information or to apply you may contact:

Assistance Program	Phone	Internet	Address
Free Medication Program	646 205-8000	freemedicationprogram.com	1632 York Ave. N.Y., N.Y. 10028
Medicine Bridge	877 667-6337	medicinebridge.com	PO Box 202318 Austin, TX 78720
Rx Solutions	800 562-6223	RxSolutions.com	PO Box 509075 San Diego, CA 92150
Peoples Prescription Plan	800 667-6914	peoplesrxcard.com	
RxHope	908 850-8004	Rxhope.com	254 Mountain Ave. Building B Suite 200 Hackettstown, NJ 07840

Partnership for Prescription Assistance

1-888-477-2669

www.pparx.org

1100 15th Street NW
Washington, DC 20005

Additional online pharmaceutical assistance programs and additional discounted drug programs can also be found on the following websites:

helpingpatients.org or phone PhRMA at 1 800 762-4636

needymeds.com

pharmhelp.info

rxhope.com

RxAssist.org

benefitscheckup.org

getfreemed.com

AARPpharmacy.com

Costco.com

Walmart.com

Ask the MD

By Jorge L. Juncos, M.D.

I was just diagnosed with Parkinson's disease (PD). Should I be placed on Sinemet right away?

Carbidopa-levodopa or Sinemet® is certainly one option. Some experts favor this option in older patients already on multiple medications, and in those who may be having memory problems. Another starting option is the use of dopamine agonists (DAs) instead of carbidopa-levodopa. This strategy is preferred in those at especially high risk of developing drug-induced motor fluctuations and dyskinesias. High risk patients include those with young onset, tremor predominant PD with dystonic symptoms. Well conducted studies have shown that DAs monotherapy (i.e., DAs only) early in the course of the illness can delay the onset of these motor complications such as wearing off (a progressive shortening on the effects of levodopa) and dyskinesias (writhing or dance-like movements that suggest overmedication or abrupt transitions from the off to on state, and vice versa) compared to carbidopa-levodopa. It is important to clarify that these are not just drug-induced problems. The appearance is also a function of individual differences among patients and disease progression. In addition, most patients on DA monotherapy will need to start carbidopa-levodopa therapy within 2-5 years of initiating treatment with DAs. Thus DA monotherapy can delay the onset but not prevent these complications. Other options include the use of MAO-B inhibitors, some of which have been approved for early monotherapy. Like DAs, this strategy requires the introduction of carbidopa-levodopa after a few years.

The important take home message is that, regardless of the choice of treatment, there is no justification for tolerating disability in the hope of avoiding the possibility of long term "drug-induced" complications. There is also no basis for saying that carbidopa-levodopa is "only useful for a few years" and thus should be saved until the symptoms "really warrant it." This misguided approach will only guarantee that a

patient will reach a higher level of disability sooner than one opting to be treated in a timely manner. Timely means treating as soon as PD symptoms force any compromise in activities of daily living, ability to exercise and have fun, or any loss of quality of life due to symptoms. These compromises are obvious when involving tremor, gross motor movements and gait. However, compromises due to the loss of fine motor dexterity are more insidious and thus likely to be missed. Accordingly, in deciding when to start treatment, pay attention to your gross and your fine movements. Finally, as disease modifying therapies become available, we will probably need to revise this and consider initiating treatment as soon as the diagnosis is made in order to maximize the effect of these agents on symptom progression.

Sometimes I call out at night and punch my pillow. What is the cause of this?

This may be due to several factors including the occasional nightmare or poor sleep from any cause (e.g., sleep apnea, anxiety, depression). When recurrent, in PD it is commonly due to a sleep disorders associated with the intrusion of rapid eye movement (REM) sleep into the early stages of sleep. At this stage, the muscles have not completely relaxed. Dreaming usually occurs during REM sleep. If the dream content is nightmarish and the muscles have achieved the relaxation of deep sleep, the person is NOT going to call out and jump during a scary dream. If on the other hand bad dreams start before the muscles have had a chance to relax, calling out and punching, also known as REM-related behavioral disorder or REM-BD is likely to appear. The accumulation of PD pathology in areas of brain associated with sleep is thought to mediate this phenomenon. If severe it needs to be treated because it reduces the quality and quantity of sleep. Approaches to treatment include avoiding medications that can aggravate REM-BD, and the use of long-acting benzodiazepines like clonazepam.

How is Parkinson's Disease dementia different from Alzheimer's dementia?

Patients with Parkinson's disease, a movement disorder, are at increased risk of developing dementia. Features of PD that increase the risk of dementia include advancing age, a history of treatment-associated hallucinations, increased duration and severity of PD and depression. Dementia affects up to 10% of clinic populations over age 65 and AD accounts for the vast majority of these cases. In PD the prevalence of dementia in patients over the age of 70 may as high as 75%. Given these numbers, it would be difficult to explain this higher incidence of dementia in PD based on the prevalence of AD in the elderly. The numbers in fact suggest that once a person develops a disorder of aging in the brain, he is more vulnerable to developing a second one.

The current thinking is that much of this excess of dementia in PD is attributable to Lewy body pathology. Lewy body pathology is responsible for the death of dopamine neurons in PD. When this pathology extends beyond dopamine neurons to involve the frontal cortex and other memory and cognitive centers, patients go on to develop a different kind of dementia termed Lewy body dementia (LBD). The most obvious difference between LBD and AD is the presence of parkinsonian features in LBD. However, mild parkinsonian features may be present in up to 20% of AD patients. Memory problems are prominent in both conditions. In AD, patients experience problems forming and retrieving new and eventually old memories from the outset. In early LBD, patients have more difficulty retrieving than forming memories. Thus they may perform as poorly if not worse than AD patients in tasks that involve the spontaneous generation of words. Interestingly, language fluency is otherwise less impaired than in AD. Patients with early AD frequently have problems with verbal expression and comprehension (aphasia), something seen only in more

advanced stages of LBD. As a consequence, there is often a discrepancy between how well a patient may look to the casual observer and the functional impairment the families witness at home. The impairment comes in the form of loss of interest ("apathy"), volitional drive ("intention deficit") and executive dysfunction. The first two are more common in early LBD than in AD. Executive dysfunction is a disabling feature of both that leads to deficits in organization, planning, and in the ability to follow through any plans. Finally LBD patients retain math skills better and are able to recognize family and friends much longer into the illness than patients with AD.

Other features of LBD that may help differentiate it from AD are wide fluctuations in wakefulness and cognition. These fluctuations give the impression that someone is "tampering with the patient's power supply". For instance, a patient who may appear normal on a given day may be hardly functional the next. Early on, patients with LBD tend to have more psychiatric disturbances than patients with AD. In AD psychiatric problems more closely follow cognitive impairment. These psychiatric problems include anxiety, depression, spontaneous and drug-induced visual hallucinations and severe sleep disturbances. Finally, and unlike patients with AD, patients with LBD have to contend with the potential cognitive and psychiatric side effects of most antiparkinsonian drugs.

As the dementia progresses, it becomes more difficult to tell LBD and AD apart. We suspect this is due to a progressive overlap in their respective pathologies. The relative silver lining to this overlap is that patients with LBD respond as well if not better to the treatments that have been developed for AD. Thus in the future they will continue to benefit from the extensive research being conducted in AD.

Senior Drivers: Staying Safe on the Road

Senior Drivers: Staying Safe on the Road

After she pondered the fact that she learned how to drive as a teenager, 72-year-old Marjorie Butler Norrie signed up for the AARP Driver Safety Program refresher course.

“We think that we’re driving like we used to drive, but [I learned] our reactions have slowed down so much, not realizing that we don’t react as well as we used to,” says Butler Norrie, who resides in Wenatchee, Wash.

In the class, Butler Norrie learned about age-related changes that can affect her driving abilities. Perhaps these shifts are why she had already begun to limit her driving. She rarely travels on big city freeways, and she didn’t drive for a month last winter, saying snowy conditions kept her off the road.

This self-restriction and self-assessment are common and healthy practices for older drivers. Examining your own driving proficiency can keep you safe. After age 75, the risk of being in a collision increases for every mile a person drives, according to the Insurance Institute for Highway Safety. Statistically, this age group falls just below teenagers for the number of fatal crashes. Although this ominous fact is linked to an older person’s ability to endure injury, older drivers—and their loved ones—need to pay attention to driving skills and make the appropriate adjustments, whether that means adapting their driving habits or hanging up their car keys for good.

A Self-Assessment Tool

The AAA Roadwise Review, available on CD-ROM from AAA.com, measures functional abilities shown to be the strongest predictors of crash risk among older drivers:

- Leg strength and general mobility
- Head/neck flexibility
- High- and low-contrast visual acuity
- Working memory
- Visualization of missing information
- Visual search
- Useful field of view

Age-related changes

As people age, the following can affect their driving abilities:

- **Vision and hearing:** Vision declines with age due to physiologic changes and to diseases such as glaucoma. Regular hearing check-ups are imperative, since safe driving means hearing emergency sirens, honking, and sounds such as bells at railroad crossing.
- **Cognition:** When you drive, you need to integrate several skills at the same time, including memory, visual processing, and attention. Both our speed of processing and judgment can become impaired, jeopardizing driving skills.
- **Motor function:** As people age, their joints become stiffer, muscles weaken and flexibility lessens. Turning your head to view traffic, using the steering wheel, and operating the gas and brake pedals can become more difficult.
- **Medications:** Certain medications can reduce driving skills, including antihistamines, sleep aids, and medications for depression, diabetes, and pain reduction. Always ask your doctor how new medications will affect your driving.
- **Medical conditions that can hamper driving abilities include:** ALS, Alzheimer’s disease, dementia and memory disorders, diabetes, head trauma, high- or low blood pressure, multiple sclerosis, nervous system disorders, Parkinson’s disease, severe arthritis, severe depression, sleep disorders, stroke effects, surgery after effects, thyroid disease, and the use of medical devices including automatic defibrillators and pacemakers.

But age also reaps experience. “Older drivers have wisdom that may make them much better drivers. Teenagers don’t have years of driving behind them,” says Lissa Kapust, the Clinical Coordinator of DriveWise, a driving fitness evaluation program at Boston’s Beth Israel

Deaconess Medical Center. “Older drivers who do self-monitoring—if they are tired or the weather is bad—this can be a critical factor in maintaining safety.”

Driving Classes

Taking a class is a good way to assess your own skills and stay safe on the road. The 27-year-old AARP Driver Safety Program refresher course is the first and largest course created for adults 50 and older. The 8-hour low-cost course is usually taught in two four-hour sessions, or people can complete an online course in a 30-day timeframe (call toll-free at (888) 227-7669). Upon completion, most auto insurance companies provide a discount. “We assess our health from time to time; we should assess our driving from time to time and make adjustments based on our assessment of our own driving,” says Brian Greenberg, Coordinator for the AARP Driver Safety Program. “Just think of it as a driver tune-up.” The class looks at 15 warning signals that might mean a person should limit or stop driving. According to Greenberg, the following five warning signs signal the need for a formal driving assessment:

1. Frequent dents or scrapes on the car or on fences, garage doors, curbs, etc.
2. More traffic tickets or warnings in the last year or two
3. Having crashes, minor accidents, or almost crashing
4. Trouble paying attention to or missing signals, road signs, and pavement markings
5. Difficulty staying in the lane of travel or changing lanes

Professional assessments

Perhaps you have noticed a loved one’s deteriorating driving abilities, but she denies any problem during conversations. An independent, objective evaluation can both judge driving competence and give a voice of authority to a decision. Completed at rehabilitation centers, hospitals, and Veterans Administration Medical Centers, these tests are usually administered by occupational therapists or driver rehabilitation specialists. Because medical providers realize they can test a patient’s hearing and vision but cannot judge his driving skills, your loved one’s doctor may be able and willing to give you a referral for an assessment. “It’s such an important decision, physicians don’t want to err on the side of prematurely taking away a license, and they don’t want to wait until it’s too late,” says Kapust. “One’s license is the most important marker for self esteem in the elderly. The loss of the license really marks the entrance into old age.”

Because people fear the end of driving, a person very rarely comes in voluntarily to a place like DriveWise. Doctors, adult children, community agencies, or a driving registry often refer people, says Kapust. A social worker begins the evaluation, discussing reasons for the referral and how the loss of driving would affect the patient. A short neuropsychological exam is given; an occupational therapist assesses the person’s vision, flexibility, strength, and cognition; and a road test is taken. Two weeks later, the patient meets with the social worker to review the DriveWise recommendations.

After an assessment, a driver often works with an occupational therapist that provides rehabilitation to strengthen skills used in driving. Often the therapist helps fit the car around the person. Devices include parabolic mirrors that yield a panoramic view; knobs or a spinner wheel on the steering wheel; and hand controls for the accelerator and brakes. Often people learn safe driving rules, such as:

- Don’t drive with the radio on or converse with your passengers or use cell phones.
- Keep your car in the best shape, with tune-ups, good windshield wipers, aligned headlights, etc.
- Always wear seatbelts.
- Drive with your headlights on.
- Make sure there is enough space between both the cars in front of you and the car behind you.

Senior Drivers

When to hang up the keys

Sometimes an assessment means the driver is told she needs to stop driving. Or perhaps a person has come to the decision on his own, realizing driving is too stressful, and it's time to retire the car keys. "Often we hear from patients and families it's a loss that they never get over. They may have a memory loss but they don't forget that somebody has taken away their keys," says Kapust.

She points out that few people will drive until they die and actively involving the person in the decision to stop driving helps. People link the cessation of driving to an end of independence, so it's important to keep people engaged in activities they enjoy, and to emphasize that retiring from driving is a normal part of aging.

Richard Hackel, a former DriveWise patient, made the decision to stop driving on his own. He suffers from ALS or Lou Gehrig's disease, and the muscles that would normally hold his left leg flat are not functional. At age 64, he worried about controlling the car in an emergency situation. "I want to live as long as I can and minimize the possibility that I could cause injury to anyone else," says Hackel, who lives in Brookline, Mass. "That loss of independence is an adjustment that everybody has to make, but I'd rather be alive and able to enjoy life than driving and risk hurting myself or someone else."

This article provided by A Place For Mom, Inc.

Disease Modification in Parkinson's Disease

Continued from cover page

everybody is in the active treatment. If the group that was initially started on placebo gets better when switched to the active drug (the symptomatic effect) but doesn't quite get as good as the group that was started on the active drug initially, one can presume there is some effect that is termed "disease modification". This is the finding that has been released by the company that makes rasagiline. In easier terms, the group that initially got the sugar pill never catches up to the rasagiline group and therefore, it is better to start rasagiline earlier.

Before everyone jumps on the bandwagon and pushes their doctor into prescribing rasagiline for them, there are some questions to consider. First, is rasagiline the only drug that does this or could it be that it is simply important to treat PD as early as possible and it does not matter which drug is picked? Second, how strong is the effect? Is it prominent enough to justify the cost of taking this medication daily and putting up with any side effects the drug might produce? Third, this study was done only in early, untreated PD. What about patients who have had PD for several years or even decades? Would the same results be seen or is it that there is only a small window of opportunity where symptoms are still mild and there is still enough production of the patient's own dopamine? Finally, just because there might be a change in level of disability, does this mean neuroprotection? It may be

that the earlier treatment reduces the stress on the brain and produces better adaptive changes that are sustained but has little to do with reduced nerve cell loss.

These are good questions to think about and discuss with your doctor. It is encouraging that we are getting to the point with PD where we understand how to do the best kinds of studies to assess disease modification and are starting to see results.

About the Author:

Holly Shill, MD, is a Sun City, AZ neurologist who is fellowship trained in movement disorders. Dr. Shill sees Parkinson disease patients at the Banner Health Research Institute. She can be reached at 623-876-5328.

This article is reprinted with permission from the Fall 2008 Power Over Parkinson's newsletter, a publication of the Arizona Chapter of APDA.

Current Clinical Trials at Emory University

Study of Antidepressants in Parkinson's Disease (SAD-PD)

SAD-PD is a research study examining the effects of antidepressants on depressed people with Parkinson's disease (PD).

Study involvement spans 12 weeks and includes 7 doctor's visits, and will study the effects of Paxil and Effexor XR versus a placebo (sugar pill) on the emotional and physical symptoms of PD. To be eligible you must: be 30 years or older, diagnosed with PD and experiencing symptoms of depression.

For more information, call Research Coordinator Barbara Sommerfeld, RN at 404-728-6944

PD patients with Parkinson's disease and Motor (movement) Fluctuations

Parkinson's patients who experience movement "OFF" time about 2-1/2 hours per day may be eligible to participate in a clinical research study for an investigational medication. This study is to demonstrate that the investigational medication will reduce the "OFF" time and improve PD symptoms.

INCLUSION CRITERIA:

- PD diagnosis
- Experience 2-1/2 hours of "OFF" time per day
- On stable doses of anti-Parkinson's medication prior to study entry
- Be able to fill out movement diaries on your daily level of function

EXCLUSION CRITERIA

Currently on dopamine agonist therapy (Requip, Mirapex)
Prior exposure to Neupro patch

For more information, call Research Coordinator Barbara Sommerfeld, RN at 404-728-6944

The NIH is sponsoring a study of the impact of creatine, an investigational drug, on slowing the clinical decline in patients with PD.

In this study, doctors will follow the progress of participants for a minimum of five years, performing physical exams, tests of thinking, mood and evaluations of quality of life to monitor for signs of the disease progression. Researchers will study whether the progression of the disease is slower in people taking creatine compared to those who are taking a placebo (inactive substance).

Key Inclusion Criteria:

- Have been diagnosed with PD within the last 5 years
- Have been using medication to treat the symptoms for more than 90 days but less than 2 years

Key Exclusion Criteria:

- Have unstable medical conditions
- Have an intolerance to creatine

For more information, please contact 404-728-4982

Study of Co-Enzyme Q10 in Patients with Parkinson's disease

Purpose: Can Co-Q10 slow the progression in patients with early, untreated Parkinson's disease.

INCLUSION CRITERIA:

- Men and women 30 years of age or older
- Diagnosed with Parkinson's disease within 5 years
- Not currently on Co-Q 10 (prior exposure is okay- washout depends on previous dosage)

EXCLUSION CRITERIA:

Current treatment or treatment greater than 90 days on any Parkinson's disease medication.

For more information, call Research Coordinator Barbara Sommerfeld, RN at 404-728-6944

PARS study:

For first-degree relatives of Parkinson disease patients in order to better understand who is at risk for PD before it starts. This is a test of the sense of smell. After completing a form with contact information, a scratch and sniff smell test and brief questionnaire will be sent to you at home. You may be contacted to continue the mail-in questionnaires annually or to be evaluated by a neurologist near your home. Some individuals may be asked to undergo more extensive testing. The level of your participation is optional.

Contact Linda McGinn, R.N. at 404-728-6427
Primary Investigator: Marian Evatt, M.D.

Why Consider Taking Part in a Clinical Trial?

There is widespread agreement among physicians and people living with Parkinson's that clinical studies are necessary to find better treatments for Parkinson's disease (PD). In fact, recent surveys have shown that 80 percent of people with Parkinson's would participate in a clinical trial if one were available in their area. Many people with Parkinson's, however, are not aware of the different types of clinical studies available. For example, often people do not know that while some studies test specific drugs, others focus on the potential benefits of exercise or the environmental and genetic links to PD.

No matter what type of study one chooses to be involved with, the experience can have many benefits. By participating in a clinical study you will:

- Increase your knowledge and understanding of PD and how it specifically affects you.
- Have access to leading healthcare professionals, quality care and potentially useful therapies.

- Personally contribute to accelerating development of treatments for PD.

In the words of Peggy Willocks, a person living with Parkinson's and clinical trial participant: "When I was first diagnosed with Parkinson's, I wanted to know everything about the disease that there was to know. Being in a clinical trial has put me in touch with those who are at the cutting edge of research in Parkinson's."

To learn more about clinical studies and review a nationwide list of trials by that are currently seeking participants visit www.PDtrials.org.

APDA is a collaborating organization with PD trials to increase education and awareness about clinical research.

What happens in a Support Group?

By Eileen Piasecki, RN, LCSW

Support groups are many things to many people. Primarily support means acceptance, encouragement and caring. I've had the privilege of facilitating a Parkinson's disease support group for nearly three years and the first thing we do is to welcome all members. Some have been coming ten years or more and others are brand new and have a million questions. We introduce ourselves telling a little about how long we've either had Parkinson's Disease (PD) or if we're there to support someone. At some meetings, this going-around-the-table offers the perfect opportunity to open up discussions of interest to members. This is a very important component of the group -- the sharing of information, net working among members, and learning you are not alone. Once this gets going there's the temptation to splinter off into side discussions. Sometimes it's important for the caregivers to have their own group to deal with their issues and concerns and so we divide up into two groups: those with PD and those without.

Information and education are another important aspect of support groups. Speakers present us with important knowledge and resources from a variety of venues and disciplines. In 2008, our group has

hosted or will host meetings with a focus on exercise, voice technique, medications and alternative forms of treatment, scams, physical therapy, occupational therapies, and even a visit from the president of the GA Chapter of the APDA, Annemarie Schwarzkopf. Also, we have a library cupboard of pamphlets, books and videos on PD topics.

The last, but perhaps the most important thing that happens in a support group is the camaraderie that is built among the members. This takes time, but it is well worth it and essential to our well being. To know that we are not alone and can share our stories with others who truly know what we're going through, is what a support group is all about. It can bring about a deep acceptance and a light hearted feeling to face the future ... even with a sense of humor.

Fundraiser

WILKINS MEDIA COMPANY, A TEAM FOX MEMBER, RAISES OVER \$50,000 AT POLO FOR PARKINSON'S EVENT BENEFITING THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

The September 28th fundraiser held at Chukkar Farm & Polo Club in Alpharetta, GA featured a rousing polo match pitting Team Fox vs. the Scuppernong Polo Club. The first game ball was thrown in from a brand-new Land Rover by Platinum Sponsor Hennessey Land Rover North Point. In the end, Team Fox emerged the solid victor with a score of 13 to 7.

Participants enjoyed burgers and hot dogs generously provided by The Varsity; an extensive silent auction with a number of unique and valuable items; raffles; halftime divot stomping and a Best Hat contest. "What a fantastic event," said Jorge Juncos, MD, Neurologist & APDA Information and Referral Center Medical Director at Emory University. "Thank you for your steadfast support for Parkinson's research."

Sandy Drayton, VP Communications for the Michael J. Fox Foundation flew in from New York to attend the event, and said,

"We are very grateful for the passion that Wilkins Media brings to Team Fox and congratulate them on an outstanding event! Polo for Parkinson's has raised both awareness and critically needed funds to help MJFF make Parkinson's a disease of the past."

Scientists believe that, with proper research funding, a cure for Parkinson's disease is within reach. The opportunity for therapeutic breakthroughs has never been greater and advances in Parkinson's research are likely to significantly contribute to the understanding of other devastating neurological diseases such as Alzheimer's, ALS and Multiple Sclerosis.

Wilkins Media Company would like to thank all of the sponsors who contributed so generously, the volunteers, the polo players, and the participants who came out to support the fight against Parkinson's disease. Bill Wilkins, Chairman & CEO, says "Look for details on our second annual event to be announced in early 2009!"





Left to Right: Sandy Drayton, VP of Communications, Michael J. Fox Foundation, New York NY
Bill Wilkins, Chairman, Wilkins Media Company
Annemarie Swartzkoff, President, American Parkinson's Disease Association, GA Chapter
Dr. Jorge Juncos, MD, Neurologist and Medical Director at Emory University Hospital
Kris Hall, Sr. VP Marketing, Wilkins Media Company



Silent auction



American Parkinson Disease Association
Georgia Chapter and
The Information and Referral Center
at Emory University
P.O. Box 49416
Atlanta, GA 30359

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MARK YOUR CALENDAR!

The next Educational Meetings are located at Clairmont Oaks in Decatur, GA

November 15, 2008

Disease Modification in PD by Dr. Ray Watts

****No meeting in December****

January 17, 2009

Acupuncture and it's effects on PD by Dr. Anna Kelly

February 21, 2009

Motor Fluctuations in PD by Dr. Jorge Juncos

March 21, 2009

Ask the MD by Dr. Stewart Factor.

April 18, 2009

Speaker to be announced

May 16, 2009

Speaker to be announced

Educational meetings will start at 10:30am. Please come prepared with your questions.

OTHER EVENTS:

November 1, 2008

Fall Gala Fundraiser

March 14-16, 2009

4th Annual golf tournament at Smokerise



This newsletter made possible by an educational grant from UCB

DISCLAIMER

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.