Spring 2009

Parkinson's OUs Spring 2009 Newsletter



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NEURO-OPHTHALMOLOGY AND PARKINSON'S DISEASE

By Andrew A. Berman, MD

Neuro-ophthalmology is a medical speciality studying the impact of neurological diseases on vision. A neuro-ophthalmologist is either an ophthalmologist or neurologist who has additional training and expertise in problems of the eye and nervous system. Neuro-ophthalmologists attempt to bridge the gap between the two disciplines by diagnosing and treating the visual manifestations of neurological disease.

Parkinson's disease (PD) is a neurological disorder caused by the death of dopaminergic neurons in the substantia nigra and therefore lowers production of dopamine in the putamen as well as the visual cortex and some cells in the retina. Also it is known that 75% of patients may have oculomotor signs (relating to movements of the eye ball) and most patients will have ophthalmic complaints such as blurred vision, trouble reading, double vision and dry eyes. For these reasons a neuro-ophthalmologist is frequently asked to care for the PD patient.

Eve Movements

There are three fundamental types of eye movements. Saccadic eye movements are the rapid involuntary eye movements that redirect our gaze to pick up an object of interest. They are important in following the lines of a printed page when reading. Secondly, there are the pursuit eye movements which will stabilize (fix) an object on our retina and follow it as it moves slowly through space. Thirdly, the vergence eye movements move the eyes in different directions, either together (convergence) or apart (divergence), keeping the image moving toward or

away from our eyes stable on the retina and avoiding double vision.

In PD the saccades tend to slow (hypometric) and show delayed initiation. Some patients will require a blink to change their saccadic position (this is called Wilson's sign). As you can imagine, this makes it hard to fixate upon changing targets in the environment and to read, as well. Often these problems can normalize with L-dopa, but if one has Levodopa induced dyskinesia, the saccades can become hypermetric (fast).

The pursuit gain becomes decreased causing what is called cog-wheel (jerky) slow-eye movements. Finally, insufficient convergence of the eyes causes eyestrain, headaches and double vision when working on near tasks. It is also common to have some insufficiency of accommodation. The eye response to a near stimulus is accommodation, of which convergence is a part. This, too will cause problems with reading and double vision.

External Eye Disease

Evelid abnormalities are common in Parkinson's disease. The blink reflex, which is normally about 16 to 18 times per minute, may decrease to one to two times per minute. This causes the ocular surface to become dry in the setting of already reduced and abnormal tear film production. The dryness leads to a foreign body sensation, blurred vision, itching and burning. Some suggest that this may contribute to excessive blinking and lid spasms, called benign

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PRESIDENT'S CORNER

Dear Friends,

Just a quick update to let you know that we are still working hard on raising money to support our various programs! We really appreciate our many volunteers who help us in these efforts. As you know our organization is run primarily by this volunteer force!

We are also working on building our Board of Directors to include people from a wide range of professions. Over the past year we have added several new members from the business, financial and senior provider services community.

Our current support groups are going strong and there is interest from many different areas of town for starting new ones. We would love some help with this too.

As always, please let me know if you are interested in helping out or if you have some suggestions for making our chapter even better. Be sure to visit our website and give us feedback.

Thanks and best wishes,

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

NIH FUNDED STUDY OF COENZYME Q10 IN EARLY PARKINSON'S UNDERWAY

Coenzyme Q10, also known as CoQ10, is a naturally occurring chemical first discovered in 1957. CoQ10 is made and is present in every cell in humans. It is sold as a nutritional supplement, and studies have suggested it may be beneficial for managing a wide variety of conditions, including: high blood pressure, migraine headaches, side effects of cholesterol-lowering medications, heart failure and PD.

CoQ10 is an important link in the chain of chemical reactions that produce 95% of the human body's energy, and may improve the function of mitochondria (the "power plants" that produce energy in cells). CoQ10 is also a potent antioxidant - a chemical that "mops up" potentially harmful chemicals generated during normal metabolism. Levels of CoQ10 in the body decline with age. Previous studies showed that CoQ10 levels in mitochondria from PD patients are reduced and that mitochondrial function in these patients is impaired. Animal studies have shown that CoQ10 can protect the area of the brain that is damaged in PD.

Thus, it seems reasonable to consider trying to give PD patients extra CoQ10, either in foods or supplements to try to boost mitrochondial functioning and provide antioxidant protection. Though some foods, like raw mackerel and herring, contain relatively high amounts of CoQ10, frying may reduce content by 14-32% and it does not appear feasible to alter diet to boost levels. In its purified form, CoQ10 is a powder that does not dissolve in water or in lipids (fats), and it is very poorly absorbed in the gastrointestinal tract. Furthermore, CoQ10 supplements are costly, so in our current economic situation, it is critical to determine whether it is worthwhile spending money on CoQ10 supplements or whether we should be spending that money for treatments proven to be effective. Because CoQ10 is classified as a dietary supplement, it is not regulated by the U.S. Food and Drug Administration. The versions of the supplement sold in stores may differ and may not contain potentially beneficial amounts of CoQ10. Early studies by Dr. Clifford Shults and his colleagues first had to demonstrate that taking a specific formulation of the CoQ10 did significantly increase the level of CoQ10 in the blood in PD patients and was well-tolerated.

Many of you may remember the excitement caused when an early study of CoQ10 that was completed in 80 patients with early PD and the results were published in 2002. Although only preliminary, this pilot study suggested that patients who received large doses of CoQ10 (1,200 mg/day) might have 44 percent less decline in mental function, motor (movement) function, and ability to carry out such activities of daily living as feeding or dressing themselves. However, because humans are not all the same, at least 1-2 larger, more definitive studies – often termed "pivotal clinical trials" -- must be completed and show similar results before researchers can say the results of that early study were not due to coincidence. Several researchers in the Parkinson's Study Group (PSG) received funding from the National Institutes of Health (NIH) to conduct such a pivotal clinical trial of CoQ10 in early PD. This trial has been nicknamed QE3 because it is the 3rd study of CoQ10 in PD by done by the PSG. (The NIH is the group of government funded agencies that fund a large portion of medical research in the United States.)

That QE3 study CoQ10 in PD was originally scheduled to start in 2005, but was delayed for two reasons: The FDA (Food and Drug Administration) wanted the 1) investigators to complete more extensive preliminary studies in animals on the possible toxicity of CoQ10 in animals because the new study was going to use doses that were much higher than those used in the pilot study, and 2) the wafers of CoQ10 that were to be used in QE3 contained high doses of vitamin E, another powerful antioxidant vitamin/supplement. The FDA was worried because during that

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NIH FUNDED STUDY OF COENZYME Q10 IN EARLY PARKINSON'S UNDERWAY (CON'T)

time, several other studies of vitamin E supplement that were done in non-Parkinson's disease populations suggested that taking vitamin E supplements might increase a person's risk of disease, not decrease it. The additional toxicology data has shown no increased risk of CoQ10 in the higher doses. The investigators reviewed data from other studies of high doses of vitamin E in patients with PD and found no evidence of increased risk of using vitamin E in PD.

Now, the QE3 study is off "hold" status and Enrollment began in January 2009 at approximately 60 clinical sites in the United States and Canada. Participants 30 years of age or older, diagnosed with Parkinson disease within the last 5 years, and are not yet receiving symptomatic treatment may be eligible for the study. Study doctors will follow participants every four months over a 16 month period. Researchers at will enroll a total of 600 research subjects with early signs of Parkinson disease.

This study is sponsored by the National Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health (NIH). If you are interested in learning more about this study, please contact the Parkinson Study Group toll free at 1-888-887-3774. This trial is also listed on the ClinicalTrials.gov web site. For a list of participating centers, see the QE3 Participating Site List. (At Emory, contact Study Coordinator Barbara Sommerfeld @ 404-728 6944 for more information to participate in this study)



Have you seen these Billboards?!!!!

They are all over metro Atlanta spreading the word about APDA. We want to say THANK YOU to Olympus Media, Wilkins Media Company, Lamar and Commerce Color for making them possible!













NEURO-OPHTHALMOLOGY AND PARKINSON'S DISEASE (CON'T)

By Andrew A. Berman, MD

essential blepharospasm. Others with PD can develop apraxia, which is an inability to open the eyes voluntarily.

As a result of the dysfunction of the autonomic nervous system (the nerves that regulate automatic functions of the body), there is frequently seborrheic blepharitis (eyelid irritation associated with oily facial skin) and dermatitis. There also can be inflammation of the cornea and ocular surface. This exacerbates the symptoms of dry eyes.

Sensory Deficits

As there are dopominergic receptors in the retina, the dysfunction can lead to a loss of contrast sensitivity. There can also be color vision deficits, usually along the blue-yellow axis in Parkinson's disease patients. Others may hallucinate, possibly due to their medications but also possibly because of age and visual disturbance.

Management

As physicians, we always have to be aware of our patients' medications - their dosages, effects and side effects. This is also true with Parkinson's disease. A good history of medications is paramount. It is important to know the symptoms are affected by the dosage and by the schedule of medication. For instance, I have patients who need different types of glasses depending upon where they are in their medication cycle.

First and foremost, the management of vision requires an accurate and thorough eye examination and correction of refractive errors. Most of the time, when eye movement abnormalities are found, it is best to prescribe one pair of glasses for distance and another for reading. This is in preference to single bifocal glasses. However, if patients insist on bifocals, then I will recommend a standard "lined" bifocal rather than a progressive bifocal. For those with convergence insufficiency, I will prescribe prisms in their glasses. Prisms help to bend light to the proper focal point on the retina when the eyes cannot move properly to accomplish the same thing. This helps with the ocular fatigue and diplopia often experienced by my patients.

The management of ocular external disease and dry eyes is constant. These conditions cannot be cured. This management usually involves warm, moist compresses, hygienic lid scrubs, and at times, medicated ointments. Dry eyes can be treated with artificial tear substitutes in both an eyedrop and ointment form. At times I will perform punctal occlusion (that is, block the drainage opening) because it will increase the contact time of the tears with the ocular surface. All of these techniques can go a long way toward making the eyes look and feel better, as well as increase a patient's vision.

The Parkinson's disease patients who suffer from blepharospasm may benefit from injections of botulinum toxin (Botox). Although it is usually repeated every three to four months, it can be very helpful in restoring a patient's ability to function. Similarly, those who suffer from apraxia of the eyelid (inability to open) can get lid crutches or cosmetic lid tape to help keep their eyes open. It is difficult to treat the sensory deficits which at times can affect people with PD. Sometimes certain tints for lenses can be helpful, and hallucinations may respond to some central nervous system depressants.

Finally, in addition to everything already discussed, the patient with PD can still get the garden-variety eye diseases. Diseases such as glaucoma, cataracts and macular degeneration must also be properly diagnosed and managed. With the proper attention to the particular problems faced by these patients, as well as their routine eyecare needs, patients with Parkinson's disease and their families can enjoy a fine quality of life.

APDA Note: If you or your health care professional would like to find a neuro-ophthalmologist in your area, you can go to the North American Neuro-Ophthalmology Society (NANOS) website www.nanosweb,org and click of Physician Referral

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2009 DRIVING PARKINSON'S AWAY GOLF TOURNAMENT

The event weekend began with a dinner/live auction at the Smoke Rise Golf & Country Club. With 80 people in attendance, everyone enjoyed the great food and fellowship. Scottie Chesin, Auctioneer, did an awesome job with the live auction. Guests walked away with some great deals from the live & silent auction which brought in over \$10,000.00 from the auction alone.

As you well know, that was the weekend it rained. After arriving at the golf course on Sunday morning and seeing the standing water on the course and the rain still coming down, the decision was made to postpone the tournament and reschedule for April 5th & 6th. Several teams had to back out with that being Spring Break for some of the schools. However, there is a silver lining in this case in that 3 additional hole sponsors signed up and a couple of teams that could not play before. We look forward to a great tournament.

The golf tournament is our biggest fundraiser for the year. The event helps raise awareness and funds to support APDA's leadership work in scientific research, education, and patient/caregiver support.

Thanks to everyone that has supported this event by attending the dinner/auction, donating items, sponsorships or in-kind donations. You are helping us meet our mission to "Ease the Burden –Find the Cure" for Parkinson's disease.

IN HONOR OF BILL AND FAYE PENDER

This year's tournament is dedicated to a wonderful couple, Bill and Faye Pender. They always greet you with a smile and a friendly hello.

Bill has been very instrumental in making the "Driving Parkinson's Away" golf tournament the success it is today. He is a tireless volunteer and inspires us all to work harder.

We thank you, Bill and Faye....for your courageous battle, for supporting this event year after year... giving of yourself and getting others involved in the fight to "Drive Parkinson's Away". Words cannot express our appreciation for what you have given back to the Parkinson's community and what you continue to give day after day.



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THANK YOU TO OUR GOLF TOURNAMENT SPONSORS



CYCLE FOR PARKINSON'S

On June 28, 2009 Frazier Cycling will hold the 4th Annual Allgood Cycle for Parkinsons Cycling Race at Georgia Gwinnett College. Allgood Pest Solutions as title sponsor and Georgia Gwinnett College as venue host have been committed to this PD fundraising event since it started in 2006. Partnering with Frazier Cycling are Top View Sports and Gwinnett Sports Commission. Come join us for an exciting spectator-friendly family event that is sure to be very fast and fun. For more information, visit our website at www.apdageorgia.org.



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YOUNG ONSET PARKINSON CONFERENCES: A FIRST-EVER COLLABORATION

American Parkinson Disease Association (APDA) and National Parkinson Foundation (NPF) Announce Plans to Co-Sponsor a Series of Young Onset Parkinson Conferences; First to be held in Dallas, October 23-24, 2009

Staten Island, NY; Miami, FL—March 13, 2009— The American Parkinson Disease Association's (APDA) National Young Onset Center and the National Parkinson Foundation's (NPF) Young Onset Parkinson Network announced their first joint collaboration today. APDA and NPF will co-sponsor a series of conferences for those living with youngonset Parkinson's disease and their caregivers. The first conference will be held in Dallas, Texas on October 23-24, 2009, with three additional programs in other parts of the country slated for the following year.

"We are pleased to be partnering with APDA to help people with young-onset Parkinson's disease nationwide. Our goal is to leverage the strong networks of both organizations to offer high-quality educational and networking experience that is so critical for people who will live decades with the disease," said Joyce Oberdorf, NPF President and CEO. Ms. Oberdorf noted that the regional series builds on the success of NPF's highly regarded national Young-Onset Parkinson Network conference, while recognizing that in the current economic environment, travel to a single national event is difficult for many people and their families.

According to researchers, between five and 10 percent of Parkinson's patients are diagnosed under the age of 40; although recent clinical studies show that as many as 12 percent of patients report that their symptoms began in their 40's. Young-onset patients will face a greater range of issues than more typical older idiopathic PD patients, including loss of employment, managing finances and concern of young families as well as the social isolation many feel is their greatest burden. Since they will live decades with the disease, and may suffer more severe treatment-related motor complications, early and intentional management is crucial to maintaining quality of life.

"APDA has been providing services dedicated to the particular challenges of young people diagnosed with PD for almost two decades through an Information & Referral Center and for the past two years by the country's only national center," said Joel Gerstel, APDA executive director. "We have sponsored regional family retreats for young patients on the West and Gulf coasts, and welcome this opportunity to join our expertise with NPF to provide even greater service to a larger number of people."

Entitled, "Choices and Connections," the one-day program also includes a live webcast to extend its audience reach to as many patients as possible. A full download of the program will also be available after the conference through both the APDA and NPF web sites.

Each program in the series is intended to combine the latest information about the science of the disease and medical updates, with panel discussions of work/disability issues, managing stress and relationships, as well as how to deal with the strains of being a caregiver. In addition, each session will offer networking opportunities as well as optional activities such as massages and exercise classes.

Both APDA and NPF have made the decision to keep registration fees as low as possible, \$30 per person, so that price will not be a barrier to attendance.

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The fee includes all conference materials as well as a welcome reception, a continental breakfast and lunch. Interested participants will be able to register online at the APDA Young Onset Center's web site www.youngparkinsons.org, or at the NPF web site www.parkinson.org.

About APDA

The American Parkinson Disease Association, founded in 1961 to "ease the burden –find the cure" for Parkinson's disease, is the country's largest grassroots organization serving the Parkinson's community, operating through a national network of 53 chapters, 63 Information and Referral centers and approximately 1,000 support groups. APDA focuses on funding research, patient/caregiver support, education and raising public awareness about the disease. Additional information is available at 800-223-2732 or visit www.apdaparkinson.org. young people with PD, their families and their health care providers with the most relevant and timely education, networking and wellness information. For more information, visit www.youngparkinsons.org, or call 877-223-3801.

About NPF

Founded in 1957 and headquartered in Miami, the National Parkinson Foundation has an extensive grassroots network of centers, chapters and support groups in the U.S., Canada, and internationally. Since 1984, NPF has invested over \$140 million in disease-related programs and is committed to increasing the quality of care for Parkinson's patients through research, education and outreach. For more information, visit www.parkinson.org, or call 800-327-4545.

NPF's 2008 Young-Onset Parkinson Network (YOPN) Conference webcast is available for viewing at www.parkinson.org (Click on "Multimedia").

The APDA National Young Onset Center provides

YOUNG ONSET PARKINSON'S DISEASE RESOURCES

The American Parkinson Disease Association operates a National Young Onset Center with a full-time director dedicated solely to helping people with young onset Parkinson's disease and their families. The Center is located at Glenbrook Hospital in Glenbrook, Illinois, but offers educational and support programs and services nationwide.

APDA has recently published a new Young Parkinson's Handbook: A Guide for Patients and Their Families. This excellent book is a compilation of articles from many of the country's leading experts and is a must-have for those whose life is impacted by young onset PD.

APDA's National Young Onset Center also produces the YOUNG PARKINSON'S NEWSLETTER: Living Well & Staying Strong.

All APDA publications are available free of charge. Join the Young Onset Center's mailing list now by calling 877-223-3801 or by emailing apda@youngparkinsons.org and receive your complimentary Young Onset PD Information Packet (which includes a copy of both the handbook and the newsletter). Find other educational and support information on the Web site: www.youngparkinsons.org.

In Georgia we have a Young Onset Support Group which meets monthly on the 3rd Tuesday at Dunwoody Baptist Church. For additional information, contact Eileen Piasecki at (770) 837-9545. If there is not a Young Onset Support Group near you, consider starting one yourself—APDA's National Young Onset Center can help you.

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DEHYDRATION

Watching for signs of illness in a loved one can be challenging. Some illnesses show up quite clearly, while others have a more subtle effect on daily living. Dehydration, depending on the severity, sometimes creates only small telltale signs while having a big effect on the body, especially in the elderly.

Dehydration occurs when a person loses more water than they take in. It takes an adequate amount of fluid for the body to function properly; for example, to regulate body temperature through sweating, maintain blood pressure, and eliminate bodily waste. If severe enough, dehydration can lead to confusion, weakness, urinary tract infections, pneumonia, bedsores in bed-ridden patients, or even death. In general, a human can survive for only about four days without any fluids.

Dehydration is especially frequent in the elderly, for a number of reasons: some medications, such as for high blood pressure or anti-depressants, are diuretic; some medications may cause patients to sweat more; a person's sense of thirst becomes less acute as they age; frail seniors have a harder time getting up to get a drink when they're thirsty, or they rely on caregivers who can't sense that they need fluids; and as we age our bodies lose kidney function and are less able to conserve fluid (this is progressive from around the age of 50, but becomes more acute and noticeable over the age of 70). Illness, especially one that causes vomiting and/or diarrhea, also can cause dehydration.

"Everybody has a normal state of body water that relates to their weight. Anything below that (normal state) is dehydration; everything above it is hyperhydration," Dr. Larry Kenney, professor of physiology and kinesiology at Penn State University, explains.

That normal level of hydration varies widely from person to person. Contrary to the mantra that everyone should drink eight glasses of water every day, Kenney says there is nothing scientific to back that up. "People misinterpreted that to be, it had to be liquid and it had to be water," he says.

A person's diet can greatly affect hydration levels: fruits (especially watermelon), vegetables, and soups are mostly water-based. "Day in, day out, a lot of people get their water from foods, as well as behavioral attitudes towards food," Kenney explains. "For instance, when we walk by a water fountain, we tend to take a drink, and we tend to drink when we eat."

Kenney also takes issue with the idea of not drinking caffeinated beverages because they're dehydrating. He says the amount of caffeine in a cup of coffee or tea is relatively small, and it's made of mostly water anyway, so it will hydrate you to some degree. The same holds true for beer, he says, but there is a point at which the diuretic effect of caffeine and alcohol kicks in, so moderation is always the key.

In general, larger people need to drink more water, as do athletes and those who perspire heavily, but that may mean more or less than eight glasses a day. "There is no one-size-fits-all remedy," he says.

Instead, he recommends monitoring body weight to keep track of hydration levels. To monitor body weight, one should be weighed every morning. If they've lost two pounds or more from the day before, and especially if they feel thirsty or have a headache, they're probably dehydrated.

Mild dehydration is defined as losing 2 percent of your body weight. Severe dehydration occurs with 4 percent or greater body weight loss. Even mild dehydration can affect a person's health, especially if he already has cardiac or renal problems. "We have measured in the lab cognitive impairment," he says. "With severe dehydration, it puts a greater strain on the heart. Think of a pump trying to pump with less fluid. That would be one of the primary problems." Kenney says an active 65-year-old who exercises probably doesn't need to weigh herself every day, but a 75-year-old in a nursing home who has had issues with dehydration in the past or has had cardiac issues,

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DEHYDRATION (CON'T)

should be weighed every day.

But, don't rely on scales that also claim to measure hydration levels and body mass index. "Their accuracy is very poor; we can't use them even for research purposes," Kenney says.

Complicating matters is that signs of dehydration in younger people don't always show up in the elderly. For example, if a young person was extremely dehydrated, his skin may be wrinkled or sagging. But, that certainly wouldn't be noticed in most elderly people.

Perhaps because of that delay in diagnosis, dehydration is a frequent cause of hospitalization in the elderly (one of the ten most frequent admitting diagnoses for Medicare hospitalizations, according to the Health Care Financing Administration), and it can be life-threatening if severe enough.

Other signs of dehydration to look for: confusion, problems with walking or falling, dizziness or headaches, dry or sticky mouth and tongue, sunken eyes, inability to sweat or produce tears, rapid heart rate, low blood pressure or blood pressure drops when changing from lying to standing, and constipation or decrease in urine output. Also check for a decrease in skin turgor—pull up the skin on the back of the hand for a few seconds; if it does not return to normal within a few seconds, the person is dehydrated.

To help make sure your loved one doesn't become dehydrated, make sure he or she consumes an adequate amount of fluids during the day; eats healthy, water-content foods such as fruit, vegetables and soups; checks that urine color is light and output adequate (dark urine or infrequency of urination is a classic sign of dehydration).

Seniors also need to be educated to drink even when they're not thirsty. Keeping a water bottle next to the bed or their favorite chair could help, especially if they have mobility issues. If your loved one is in a nursing home or other care facility, make sure that the staff has a hydration program in place, including assisting residents with drinking, offering a variety of beverages (remember, taste buds change with age, so a beverage they used to enjoy may no longer taste right), and providing drinks not only at mealtimes but in between meals. Also make sure that they monitor residents' weight and assess them if their physical condition or mental state changes. If dehydration is an issue and your loved one takes laxatives or diuretics, speak to his or her doctor about changing medication. As with most illnesses, prevention is the key. Making sure your loved one stays hydrated now is much easier than treating him or her for dehydration later.

Disclaimer: Although the information contained herein is medically related, it is provided for informational and educational purposes only and should not be used, interpreted, or relied upon as professional medical advice. Only a qualified physician can diagnose and treat any medical condition. Please consult with your doctor or other qualified healthcare professional regarding any specific personal medical and health concerns you may have. While we make every effort to keep our information current, please be aware that advances in medical science are ongoing and therefore some information provided here may have become out of date since our latest review.

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DISCLOSING THE DIAGNOSIS OF PARKINSON'S DISEASE

By Terri Hosto, MSW, LCSW

Dept. of Neurology, Washington University School of Medicine, St. Louis, Mo. APDA Support Group Leader

In many instances, the benefits of informing other people about the diagnosis of your Parkinson's disease (PD) will outweigh the perceived benefits of secrecy. For example, being open about the diagnosis can eliminate the need for persons with PD to cover up or try to compensate for their difficulties. It allows them to openly discuss their symptoms rather than feel embarrassed by their need for help; likewise, by being up front about it they can save a lot of explanations about why they sometimes have trouble walking, or their handwriting becoming illegible or slowing down.

Others who are close to the person with PD may have already suspected something being wrong. Telling the truth about the diagnosis will give them correct information and help head off false assumptions. Furthermore, with the disclosure, the people with PD can openly discuss with family members and others about long-range financial plans, healthcare directives and powers-ofattorney, and how to make the best use of their time before the disease disables them.

At first, it may be hard to tell others. Before doing so, it is important to consider what information should be given and to whom. For example, the person with PD may want to tell others that PD is a degenerative disease of the brain that results in tremor, stiffness, decreased movement and unsteadiness.

The person should talk about the particular symptoms he/she is experiencing to help others better understand what is happening. Because PD affects each individual differently, there is no exact way to determine how the disease will progress. While there is no cure, some of the symptoms can be managed by medications along with changes in diet and regular exercise. Family members and others should be encouraged to obtain information about the disease and get connected with organizations like APDA. Support groups can be beneficial to persons with PD and family members.

If the person who has been diagnosed with PD is

employed, he/she should first determine his/her rights under the Americans with Disabilities Act and equal Employment Opportunity Commission before telling the employer.

The person may be able to continue working by simplifying job duties or making accommodations to the worksite. The person may have to retire early, so it is also important to gather information about the employer's early retirement policy, insurance plans and disability provisions. If the company has an Employee Assistance Program (EAP), the person with PD should consider speaking with an EAP counselor to help explore and understand his/her options. In addition, he/she should be sure to look into Social Security Disability to see what benefits they may be eligible for.

Disclosing the diagnosis can ultimately maximize the person's quality of life. With the open support of family, friends and others, persons with PD can continue enjoying the various physical, mental, social and spiritual activities that have made his/her life complete. Below is a list of resources.

Americans with Disabilities Act Web site: www.ada.gov Toll-free 1-800-514-0301 10:30 am - 4:30 pm (ET) Mon-Wed & Fri, 12:30-4:30 pm (ET) Thursday

Equal Employment Opportunity Commission Web site: www.eeoc.gov Toll-free: 1-800-669-4000 8 am - 8pm (ET)

> Social Security Administration Web site: www.ssa.gov Toll-free 1-800-772-1213 7am- 7pm, Mon-Fri

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RECIPE FOR MAINTAINING HEALTH AND HAPPINESS DESPITE HAVING P.D

By Margaret Miller

TAKE ONE PERSON WITH PARKINSON'S DISEASE, ANY AGE

SIGN HIM OR HER UP FOR A WATER AEROBICS CLASS (available at many churches, hospitals, and community organizations.)

And that's all there is to it. The rest will take care of itself. Of course, an encouraging word to the person with Parkinson's disease recognizing his water aerobics efforts is always helpful.

2009 marks my tenth anniversary since I began a regular program of water aerobics five days per week, Monday through Friday, at the Concourse Athletic Club. And what a difference it has made in my life! Obviously, the health benefits are tremendous, as participants gain core strength, maintain optimal weight, exercise without putting much pressure on the joints, and work against the resistance of the water.

You need to know that there is another benefit which, to me, is as important as any I have listed:

IT IS GREAT FUN! Being in the water seems to stimulate bonding, and people always talk about what great friends they make in water classes. Perhaps the warmth and friendship is related to our feelings of safety, comfort, and security when we were in the womb. At any rate, my water classes have a diverse group of people – men, women, young, old, pregnant, getting ready for surgery, and the like. We play together like children, telling stories, jokes, celebrating good times and getting through the not-so-good days, together. It doesn't FEEL like exercise.

Come and have a look, if you like. We're there every morning at 10:00 am. Just follow the sound of the boom box and the laughter.



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AMERICAN PARKINSON DISEASE ASSOCIATION(CON'T)

Support Group Meetings in Georgia and South Carolina

ATLANTA

APDA Educational Meeting Clairmont Oaks 441 Clairemont Avenue Decatur, GA 30030 3rd Saturday, 10:30 AM (Aug-May) Mary Louise Weeks, RN (404) 728-6552

People with Parkinson's PWP Group Westminster Presbyterian Church 1438 Sheridan Rd. NE Atlanta, GA 30324 3rd Tuesday, 1:00 PM MaryAnne Brawley (770) 554-4193

Atlanta Veterans Medical Center Veterans Learning Center, 1st floor 1670 Clairmont Road Decatur, GA 30033 1st Tuesday, 1:00PM Conetta Sam 404-321-6111 x7121

Peachtree Road United Methodist Church 3180 Peachtree Road NW Atlanta, GA 30305 3rd Tuesday at 1200-1330 Betsy Lunz 404-240-8237

ATHENS

Athens Council on Aging 135 Hoyt Street Athens, GA 30606 4th Monday, 2:30 PM Ann Boyer (706) 425-9591

BLAIRSVILLE

Union County Library Blairsville, GA 30512 2nd Wednesday, 3:00PM Paula Wilde (706) 745-6594 Peter Schltze (706) 745-9171

DOUGLASVILLE

Wellstar Medical Center 8820 Hospital Drive Douglasville, GA 30134 1st Tuesday, 2:00 PM Larry Hennessy (770) 949-9467

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DUBLIN

Laurens County Library 801 Bellevue Ave Dublin, GA 31021 2nd Monday, 10 AM Gary Gray 478-275-3058

DUNWOODY

EARLY ONSET PD GROUP Dunwoody Baptist Church 1445 Mt. Vernon Road Atlanta, Georgia 30338 3rd Tuesday, 7:00 PM Eileen Piasecki (770) 837-9545

Dunwoody United Methodist 1548 Mt. Vernon Road Dunwoody, GA 30338 2nd Monday, 7:00PM Barbara Bean 770-394-0675, ext. 119

FAYETTEVILLE

Dogwood Forest Senior Living Home 1294 Hwy 54 W Fayetteville, GA 30214 4th Tuesday, 7:00 PM Pam MacCallister (770) 487-4444 Betty Fry (770) 631-2665

FLOWERY BRANCH

Flowery Branch United Methodist Church 5212 Spring Street Flowery Branch, GA 30542 2nd Sunday at 4:00PM Gary Grizzard 678-617-2636 gldar@bellsouth.net

GAINESVILLE

St. Paul United Methodist Church 404 Washington St., First Floor Gainesville, GA 30501 First & Third Thursday, 11:00 AM Marie and Bob Bridges (770) 532-8848

GAINESVILLE

Lanier Village Estates 4511 Misty Morning Way, Apt 2118 Gainesville, GA 30506 4th Tuesday, 11:00AM , Ruth Pearce (770)718-9752

AMERICAN PARKINSON DISEASE ASSOCIATION(CON'T)

Support Group Meetings in Georgia and South Carolina

GRIFFIN

Spalding Regional Medical Center 601 S. 8th Street Griffin, GA 30224 4th Wednesday, 2:00 PM Liz Tarleton, (770)233-2001

LAWRENCEVILLE/ GWINNETT

Glancy Rehabilitation Center, Mango Room 3215 McClure Bridge Road Duluth, GA 2nd Friday, 1:30 PM Sharon Hansen (678)312-6175 shansen@gwinnettmedicalcenter.org

MACON

Medical Center Wellness Center 3797 Northside Drive Macon, GA 31210 September-May Last Thursday of the month, 3:00PM Patti Jones (478)746-9401

ROSWELL

Roswell United Methodist Church 814 Mimosa Blvd. Roswell, GA 30075 2nd Sunday (Aug. – May), 4:00 PM Julie Eckert (770) 924-6416

TIFTON

LeRoy Rogers Senior Center 315 West 2nd Street Tifton, GA 31794 2nd Tuesday, 2:00 PM (Sept-May) Linda Boyette, R.N. (229) 388-1888

Caregiver support group Well Spouse Association 4th Monday 7-8:30pm Jan Rabinowitz 404-579-6782 jhrteam@hotmail.com www.freewebs.com/atlantawsa

SOUTH CAROLINA

ANDERSON, SOUTH CAROLINA Anmed Rehab Hospital 1 Springback Way Activity Room 3rd Tuesday, 2-3:30 PM Katherine Vickerman (864)332-2850

LANCASTER, SC

Covenant Baptist Church 165 Craig Manor Road 4th Tuesday at 3pm Don Gibson 803-283-2358

MYRTLE BEACH/ MURRELL'S INLET, SC

Waccanaw Community Hospital Hwy 17 Murrell's Inlet 2nd Thursday Elaine Casavant (843) 650-8756

SPARTANBURG, SOUTH CAROLINA

Senior Centers of Spartanburg 142 S. Dean St. Spartanburg, South Carolina 29302 2nd Thursday, 3:00 PM Ethel Perricone (864) 597-1150 Norbert Collins (864) 457-2439

COLUMBIA, SOUTH CAROLINA

Lexington Medical Park Auditorium 2720 Sunset Boulevard West Columbia, SC 29169 3rd Sunday 3:00PM Dottie Gantt (803) 604-0061 lakeside@att.net www.columbiaparkinsonsupport.org

NORTH CAROLINA

Asheville Chapter 1st Tuesday 10:30-12:00PM Care Partners Health Services Seymour Auditorium Lisa Laney-Kendrick, MSW 828-277-4886

If there is not a support group in your area and you would like to start a support group, contact the Information and Referral Center at 404-728-6552

Parkinson's @ Us



American Parkinson Disease Association Georgia Chapter and The Information and Referral Center at Emory University P.O. Box 49416 Atlanta, GA 30359 Non-Profit Org. U.S. Postage PAID Atlanta, GA Permit No. 7992

MARK YOUR CALENDAR!

Upcoming APDA events: The next Educational Meetings are located at Clairmont Oaks in Decatur, GA

May 16, 2009

Nutrition in PD by Judy Tormey

*****No meetings in June or July********

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

OTHER EVENTS:



June 27 & 28, 2009 4th Annual Cycle for Parkinson's at Georgia Gwinnett College

Medtronic This newsletter made possible by an educational grant from Medtronics

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.