

APDA LAUNCHES FIRST-OF-ITS-KIND PARKINSON'S REHAB RESOURCE CENTER

*The 888-606-1688 "helpline" will connect callers
with Boston University licensed physical therapists*

Helping people who have Parkinson's disease (PD) to access information on exercise recommendations, the American Parkinson Disease Association (APDA) and Boston University have established the country's first National Resource Center for Rehabilitation. The center's toll-free helpline telephone number is 888-606-1688, and callers will be able to

Speak with a licensed physical therapist who can answer questions about exercise, provide information about programs in the caller's area and provide educational materials.

"Almost a decade ago, APDA successfully led the fight to secure physical therapy coverage for people with PD on Medicare," said Joel Gerstel, APDA's executive director.

"At the time, the benefits of exercise and physical therapy were under recognized, but today, exercise has proven a valuable tool in maintaining a healthy lifestyle for people with disease. APDA is again in the forefront by making free physical-exercise information readily available to patients, their caregivers and healthcare professionals across the

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APATHY AND FATIGUE IN PARKINSON'S DISEASE

By Laura Marsh, MD

Apathy and fatigue are two common non-motor disturbances in Parkinson's disease (PD) patients and both contribute substantially to disability. Either can appear as part of another condition, or as an independent significant symptom. Both conditions are often not diagnosed, and recognition and adjustment to them by the person with PD, the caregiver and family members is important in sustaining a good quality of life.

ment to them by the person with PD, the caregiver and family members is important in sustaining a good quality of life.

Apathy

Apathy refers to a set of behavioral, emotional and cognitive features that

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PRESIDENT'S MESSAGE

Dear Reader:



It's difficult to believe that we are at the end of the first decade of the new millennium. The numbers on the calendar continue to change, but for those with a progressive, degenerating disease, are they numbers that are leading to greater debilitation or taking us closer to finding the cure?

A realistic view of the past few years is not rosy for those with Parkinson's disease and their loved ones. Yes, there has been scientific evidence linking new possible causes such as environmental factors, widespread use of deep brain stimulation to lessen symptoms, and recent changes in the National Institutes of Health research guidelines suggesting scientists will be able to explore potential cures with greater freedom. In everyday terms, however, few new therapies have been discovered that totally eliminate physical or cognitive symptoms, substantially halt the progression of, let alone cure, the disease.

To compound the scarcity of therapeutic advancement, a globally weak economy has reduced the needed funding for greater research efforts.

But it is exactly such challenges that energize the APDA commitment.

We, like all not-for-profit organizations, are laboring under reduced revenue and ever-increasing costs. But unlike many other organizations that have eliminated research support, we continue to fund our nine APDA Centers for Advanced Research at the Universities of Alabama - Birmingham, Chicago, Pittsburgh, and

Virginia; schools of medicine at Boston and Emory universities; UCLA and Robert Wood Johnson medical school; and Washington University, and to meet our commitment to multi-year fellowships and grants. We have also increased our unique summer internship for medical students to provide young clinicians the experience of working in a research laboratory and to encourage Parkinson's disease research as a career choice.

In this issue you will read about our new free hotline, which we have created with Boston University's renowned Sargent College for Neurorehabilitation. The first of its kind, this service from qualified physical therapists will allow people with PD and caregivers immediate answers to their questions about exercise and programs in their locations.

This is the second free program to patients and caregivers that APDA has introduced during these down times. In the waning months of the last year, a free caregivers e-tool was introduced and is available on our Web site by clicking the "Ease the Burden" button.

Yes, we have been forced to make financial adjustments to continue our mission, but APDA promises it will continue to strive in the days ahead to provide patient support and programs and fund the research that ultimately would find the cure.



Joel A. Miele Sr., PE
President

What Can I Do to Help?

Lotsa Helping Hands is a private, Web-based caregiving coordination service that allows family, friends, neighbors and colleagues to create an online community to assist a family caregiver with the daily tasks that become a challenge during times of medical crisis, caregiver exhaustion, or when caring for an elderly parent.

APDA makes the service available without cost by visiting www.apdaparkinson.org, and clicking the "Ease the Burden" button on the home page.

Each community includes an intuitive group calendar for scheduling tasks such as meals delivery and rides, a platform for securely sharing vital medical, financial and legal information with designated family members, and customized sections for posting photos, well wishes, blogs, journals and messages.

Now, when someone asks, "What can I do to help?" the answer is "give me your name and e-mail address" – the system takes over and allows people to start helping. ■

APDA Launches First-of-Its-Kind Parkinson's Rehab Resource Center

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country," Gerstel said.

"Evidence supporting the benefits of exercise for people with Parkinson's disease is growing," said Terry Ellis, PT, PhD, a leader in neurological physical therapy research, and the new center's director.

Dr. Ellis is a clinical associate professor in the department of physical therapy and athletic training at the College of Health and Rehabilitation Sciences: Sargent College, Boston. The new resource is an outgrowth of the Center for Neurorehabilitation's Community Wellness Programs, which are exercise programs designed to improve mobility, quality of life and communications for persons with PD. These programs have benefited more than 400 people in 14 New England communities. "Our objective is to share this knowledge with patients, caregivers, students and healthcare professionals," she said. "This partnership with APDA, also



known for its pioneering efforts in physical therapy, will give anyone interested an easy, free pathway to the most up-to-date information."

Vlad Lyczmanenko, president of APDA's Massachusetts Chapter, which is co-funding the center, said that his chapter strongly supports the initiative. "It is imperative that people with PD are first motivated to exercise and then have access to professionals who can help them with practical information about how to exercise correctly for their particular needs."

Dr. Marie Saint Hilaire, director of the APDA Center for Advanced Research at Boston University, points out the importance of exercise in the management of PD. "Exercise helps to improve quality of life and day-to-day function in people with Parkinson's disease," said Dr. Saint Hilaire, who recommends that patients with PD consult with a physical therapist early in the disease process in order to reap the benefits right from the start.

Cathi Thomas, coordinator of the APDA Information & Referral Center at Boston University's Medical Campus, noted the value to other healthcare providers and said the center will maintain updated lists of community rehabilitation specialists. ■

"Neuropsychiatric Symptoms in Parkinson's Disease," Movement Disorders, 2009 Nov. 15; 24(13);2175-2186.

Apathy and Fatigue In Parkinson's Disease

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involve reduced interest and motivation in goal-directed behaviors, and indifference. Some studies emphasize a lack of motivation, whereas others focus on a lack of emotional responsiveness as the core feature of apathy.

Patients with apathy typically show poor motivation with reduced initiative, effort and perseverance as well as indifference to their own circumstances and a lack of curiosity about others. They may resist engaging in activities or withdraw early, show no concern for their health, and lack of interest to new experiences.

Apathy's considerable impact generally causes patients to become inactive, leading to further functional decline and greater debility.

Misattributing these signs as laziness or contrariness, family members may become frustrated, which, in turn, can lead to resentment, especially if the condition has not been diagnosed.

Fatigue

Fatigue is the single-most disabling symptom reported by up to one-third of PD patients.

Fatigue early in PD and may even predate onset of the more familiar motor symptoms such as at-rest tremors, muscle rigidity, and bradykinesia (slowness). Once present, fatigue can be chronic or intermittent, but lifetime prevalence increases over time. Fatigue in PD also is associated frequently with depression, cognitive deficits, and daytime sleepiness.

Yet, despite its prevalence and impact, fatigue is under-recognized clinically.

There are two main classifications of fatigue: peripheral and central.

Peripheral fatigue is a physiological phenomenon that involves lack of energy associated with muscular fatigue, and can be objectively measured by a clinician.

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By ENRICO FAZZINI, DO, PhD

Associate Professor of Neurology
New York University, New York
University of Nevada, Las Vegas
N.Y. Institute of Technology, Old Westbury

Q: I have had PD for several years. I am taking Requip XL, Sinemet and Sinemet CR. I am also taking Florinel and Midodrine for low blood pressure. I still get dizzy when I stand, but I do not faint anymore. I have developed twisting movements when the medications work and most recently I am starting to see figures of people who do not exist in the living room.

A: You have three complications: orthostatic blood pressure, "on" dyskinesia, and hallucinations. In general, we try to increase medications like Requip and lower Sinemet in order to combat excessive dyskinesia, but in your case the Requip may be causing the hallucinations and contributing to the low blood pressure when you stand up.

Q: On my last visit to the doctor, my Stalevo was reduced from 75 to 50mg four times a day because of too much movement. Now I am so stiff and slow; I can hardly move.

A: It seems as if you are very sensitive to L-Dopa. Even a slight lowering of L-Dopa from 75 to 50 mg every dose makes your PD symptoms come out more and the full dose of 75 mg L-Dopa in the Stalevo produces too much dyskinesia. You should keep the Stalevo at 50 and add a dopamine agonist like Requip or Mirapex and hopefully this will help to lessen the PD symptoms without increasing the dyskinesia. Another idea would be to add Azilect.

Q: I have been on Sinemet, Sinemet CR and Mirapex. I have been getting so slow in the afternoon following lunch. The medications do not last during the afternoon. I don't want to keep increasing my medication. Any suggestions?

A: Pay close attention to the timing of your doses of medications with meals. This is so important. The amount of protein in a meal and the proximity to a dose of L-Dopa can lead to a total ineffectiveness of that dose of L-Dopa. Keep your lunch proteins low and take your medications one hour before lunch or two hours after lunch. ■

Estrogen Use and Risk of Parkinson's Disease

To determine if reproductive factors or exogenous estrogen are associated with the risk of Parkinson's disease (PD), a prospective study with 22 years of follow-up was conducted among postmenopausal participants in the Nurses' Health Study.

Relative PD risks were estimated from a Cox proportional hazards model adjusting for potential confounders. Risk of PD was not significantly associated with any of the reproductive factors measured or exogenous estrogen use. Use of postmenopausal hormones, however, may modify the association of smoking and caffeine intake with PD risk. The inverse relation between smoking and PD risk was attenuated among us-

ers of post-menopausal hormones. Similar results were obtained for caffeine.

Women using progestin - only hormones were found to have an increased PD risk, but this result was based on a very small number of cases. In this large longitudinal study, we found no evidence of a beneficial effect of exogenous or endogenous estrogens on the risk of PD. The use of postmenopausal hormone use may interact with other risk factors, but findings are preliminary and need confirmation. ■

(Movement Disorders Vol. 24 P. 1359-1365 2009.)

STRETCHING YOUR DOLLARS

APDA's National Young Onset Center frequently receives calls from people with Parkinson's disease who are struggling financially. Some people are still working but trying to save as much as possible for the future, while others are trying to make ends meet on a fixed income. Either way, covering the basics can be incredibly tough for many people and families, especially in the current recession. Inflation also has a hand in making it difficult to live comfortably on a fixed income. If only dollar bills could truly be stretched!



If you do not have a personal or household budget, consider developing one. It can sometimes be hard to confront the reality of our financial situation, but it's worth it in the long run. Creating a budget can help keep track of expenses, both by category and exact dollar amounts. It can also help identify ways to decrease your spending. For example, dining out is an expense that adds up quickly. Budgeting can even improve more than your bottom line. We tend to eat healthier when we make our own meals. Not much of a chef? Have your support group exchange simple, healthy recipes. Need to run some errands? Spring will soon be upon us. Consider taking a short walk to the corner store — you can save on gas money and get in some exercise.

Obviously, medical expenses cannot be completely eliminated from a budget, but you may find that there are ways to spend less. Web sites such as Needy Meds (<http://www.needy meds.com>) not only list free and low-cost brand and generic medications, but also list free and low-cost medical clinics for those who qualify. While you're on the Internet, why not discover possible benefits and assistance for which you qualify? Web sites such as Benefits Checkup (<http://www.benefitscheckup.org>) provide a wide range of financial assistance programs that can help with housing, meals, even prescription drugs.

There are numerous assistance programs in the United States from online support groups to free home repair. While APDA does not provide financial assistance, our Information and Referral (I&R) Centers can help you find resources like those listed above. So don't be afraid to ask for what you need. You may discover resources you never knew existed. ■

Young Onset Parkinson Conference March 12-13, 2010 - Sacramento, CA co-sponsored by:



National Parkinson Foundation (NPF)

&
American Parkinson
Disease Association (APDA)

The second in a series of
conferences for those living with
Young Onset Parkinson's Disease



Total Registration fee: \$30 per person (includes reception, breakfast and lunch)

FDA Reduces Restrictions for Drug That May Slow PD Progression

The U.S. Food and Drug Administration (FDA) has approved newly revised prescribing information that reduces certain food and medication restrictions for Azilect® (rasagiline tablets).

Azilect 1 mg tablets are prescribed for treating PD symptoms both as initial therapy alone and as an addition to levodopa later in the disease.

The New England Journal of Medicine in September published results of the Attenuation of Disease progression with Azilect Given Once-daily (ADAGIO) trial, which demonstrated that patients receiving Azilect® experienced superior benefit over 18 months compared to those who started the same treatment nine months later. The ADAGIO was a randomized, multi-center, double-blind, placebo-controlled, parallel-group study

prospectively examining rasagiline's potential disease-modifying effect in 14 countries.

The new FDA guidelines reduce concerns regarding the use of Azilect together with certain medications, including many over-the-counter cough/cold medications, as well as general dietary restriction of ordinary levels of tyramine, an amino acid found in certain foods and beverages, such as air-dried and fermented meats, aged cheeses and most soybean products. Very high levels of tyramine (above 150 mg a day), however, should still be avoided by patients taking monoamine oxidase (MAO) inhibitors.

As with all medications, discussion with a physician should precede any drug or dietary changes. ■

AROUND THE COUNTRY

Walks Around the Country Support Research

Next month begins APDA's walk-a-thons, which benefit its PD research funding. Last year, these events raised approximately half a million dollars to support cutting-edge research at APDA's nine centers for advanced research, and individual scientists' research.

The walks begin in Mississippi, with its inaugural Parkinson's Forum and 5K Charity Race at scenic Lake-shore Park at the Ross Barnett Reservoir, Brandon.

Four chapters have scheduled walks in April, Parkinson's Disease Awareness Month: East Texas, April 17; and on April 18 (Parkinson's Awareness Day) Greater Los Angeles, New Mexico, and Wisconsin chapters.

May walks will take place on Long Island, N.Y. and in San Antonio, Texas, May 22.

Details on these and other APDA events can be found at www.apdaparkinson.org.

In the Midwest

APDA's Midwest Chapter began celebrating its 20th anniversary at its November board of directors meeting.



Members of the Midwest Chapter launch their 20th anniversary appropriately with a birthday cake. Maxine Dust, chapter president, shows off the cake before board members, (l-r) Paulina Donor, Sheryl Jedlinski, Joann Subaitus, JoAnn Golec, Mary Wesley, and Mike Marino begin enjoying.

Maxine Dust, who was the chapter's first secretary and subsequently has served as president for most of its existence, led the celebration by blowing out the candles of a birthday cake. Maxine has also served as the regional representative to APDA's board of directors since 1999.

The St. Louis annual fashion show is a not only a major fundraiser, but also a family event, so the 14th annual happening emphasized just that. Fathers and daughters, husbands and wives, grandparents and grandchildren joined local radio and TV personalities to entertain the more than 450 people at "These are a Few of My Favorite Things" last fall at the Sheraton

Westport Chalet-Versailles Ballroom. Dr. Joel Perlmutter, director of APDA's Center to Advanced Research at Washington University, and his wife Monica were models, and former national board of director member Dorothy Reimers served on the committee. Information & Referral Center coordinator Debbie Guyer reported that the event netted more than \$52,000.

In the West

APDA's West Coast Office honored three prominent researchers from APDA's Center for Advanced Research at UCLA's School of Medicine at a November luncheon in Los Angeles.

Drs. Marie-Francoise Chesselet, director of the center, Jeff Bronstein, researcher, clinician and medical director of APDA's Information & Referral Center, and Beate Ritz, vice chair of the UCLA epidemiology department, were recognized for their contributions to PD research.

The honorees discussed past research projects and new developments taking place, and each expressed gratitude to APDA for providing the funding that made many of their projects possible. The luncheon's \$21,000 proceeds will benefit PD research. ■



West Coast Office staff, Lisa Magana (left), and John Amber, interim director (far right), flank UCLA scientists honored at a luncheon in Los Angeles, (l-r) Drs. Beate Ritz, Jeff Bronstein and Marie-Françoise Chesselet.



St. Louis area media celebrities joining in the show's entertainment are (l-r) Michelle Anselmo, KPLR/KTVI-Fox 2, Elliot Davis, KTVI-Fox 2, and Laurie Mac, KHITS 96 Radio.



Chapter president Matt LaMartina and his daughter Payton walk down the runway during the 14th annual St. Louis fashion show.

More relevant in most cases is central fatigue, generally described as an abnormal degree of persistent tiredness, weakness, mental or physical exhaustion or both. Central fatigue is a subjective experience (in contrast to apathy, which is generally an observed phenomenon) with two subtypes, physical and mental.

Physical fatigue is a sense of physical exhaustion and lack of energy to perform physical tasks despite the ability to do so.

Mental fatigue refers to the effects experienced during and after prolonged periods of demanding cognitive activities that require sustained mental efficiency. Given its subjective nature, the overlap between physical and mental fatigue is not always clear.

Patients report fatigue onset, duration and relationship to prior activity as unpredictable, but it is often exacerbated by physical, psychological, or social stress. The inability to initiate and sustain activity associated with fatigue is distinct from sadness, sleepiness or impaired motor function.

Fatigue has adverse effects on quality of life, depression, and disability in PD and is the primary determinant of work-related disability. It is also associated with higher rates of depressive symptoms, sleep disturbances and cognitive disturbances, but it is also highly prevalent in non-depressed patients. Surprisingly, fatigue is unrelated to exercise efficiency, activity level, or physical fatigue.

Diagnosis

Both apathy and fatigue are diagnostic challenges because of their co-existence of mood symptoms and cognitive deficits, and their overlap with PD motor signs. For example, loss of motivation, a lack of effort and emotional indifference mimic bradykinesia, bradyphrenia (slowed thought process), and masked facial expression of PD in the absence of apathy. Similarly, flattened affect (the absence or near-absence of emotional

response to a situation that normally elicits emotion) and passivity can manifest as monotonous and reduced spontaneous speech.

Symptom rating scales are used to define the presence of apathy, and a number of fatigue rating scales have been developed for the general population and for specific conditions such as the Parkinson's Fatigue Scale (PFS), developed as a disease-specific scale taking into account motor symptoms.

Management

Apathy management is often difficult because patients are indifferent and their inactivity misconstrued. Non-medication strategies involve providing an individualized daily schedule and structure to help maintain a satisfactory activity level and enrichment. Possible medications include dopamine agonists, psychostimulants, modafinil (a wake-promoting drug), and testosterone. Deep brain stimulation effects are inconsistent.

Few studies have investigated fatigue treatment. In placebo-controlled trials, methylphenidate had a favorable effect on fatigue and l-dopa improved physical fatigue. Dopamine agonists have been helpful for some, but fatigue worsened in the placebo group compared to those who initiated levodopa therapy in early course untreated PD. Modafinil improved excessive daytime sleepiness but not fatigue in a double-blind placebo-controlled trial. Nocturnally-administered sodium oxybate improved fatigue and excessive daytime sleepiness in PD. ■

"Neuropsychiatric Symptoms in Parkinson's Disease," Movement Disorders, 2009 Nov. 15.

Dr. Marsh is a professor of psychiatry at Baylor College of Medicine, director of the Mental Health Care Line of the Michael E. DeBakey Veterans Affairs Medical Center, both in Houston, and a member of APDA's Scientific Advisory Board.

Compulsive Behaviors in Parkinson's Disease

Antiparkinson therapy can be the primary cause of a range of non-motor symptoms that include a set of complex disinhibitory psychomotor pathologies and are linked by their repetitive, reward or incentive – based natures. These behaviors relate to aberrant or excessive dopamine receptor stimulation and encompass impulse – control disorders, punding, and the dopamine dysregulation syndrome. Common compulsive

behaviors include pathological gambling, hypersexuality, compulsive eating, and compulsive buying.

The management of dopaminergic drug – related compulsive behaviors is discussed in the light of the current understanding of the neurobiological substrate of these disorders. ■

(Movement Disorders Vol. 11 p. 1561-1570, 2009)

PD Patients Can Benefit From Recognizing “Wearing-Off” Signs

By M. Christina Ospina, MD

Recognizing the signs and symptoms that might slowly sneak up on you between doses is an important factor for a smooth response from your Parkinson's disease (PD) medications.

The term “wearing-off” is commonly used to express the return of PD signs and symptoms between doses. It is usually caused by a gradual decline in dopamine levels in the brain.

A dose of Sinemet® that used to work for three or four hours now works only for 2.5 or 3.5 hours. At about 30 minutes before your next dose you may experience several vaguely defined signs and symptoms that you can not identify, nor know why they are happening, nor how to respond to them.

If these signs and symptoms of wearing-off continue unrecognized, and you do not adjust your PD medications, your dopamine levels will decrease to the point that you will start shaking, shuffling, freezing and experiencing full-blown PD signs and symptoms.

You need to pay attention to what your inner self is telling your body and to keep yourself in charge. You want to manage the disease, not have the disease manage you.

By listening attentively to patients, physicians have come to understand that there are several subtle things that you will be able to recognize as early signs of wearing-off:

- Your spouse is talking to you and you have no idea what he/she is saying (e.g., “I have told him about this four times in the last 30 minutes, doctor. I think he did not pay attention to anything I said!”).

- Your favorite TV program isn't funny anymore.
- You experience a sudden onset of depression and a tendency to feel like crying.
- You have to push on the armrest more than twice to get up, even though you were able to get out a chair without much difficulty a few minutes earlier.
- A sense of tightness of your neck and head has come on without warning.
- For some unexplained reason, you have difficulty finding appropriate words.
- You are reading something, when you suddenly have blurred vision or feel that some of the words are starting to move. They may even move off the page.
- You suddenly begin to stutter.
- You become restless because something inside you tells you to keep moving. You get in and out of a chair, even though you have great difficulty, then walk up and down the corridor. You go back to your chair and sit but within a few seconds feel that you have to get up and move. This phenomenon is called “Akathisia” or motor restlessness.
- The familiar symptoms of tremor, rigidity, bradykinesia (slowness of movement) and trouble with balance return.

If you suspect that you are experiencing wearing-off periods with your current medication, discuss it with your physician. ■

Dr. Ospina is a neurologist trained in movement disorders at Banner Good Samaritan Medical Center, Phoenix.

APDA Funding Leads to New Speech Tool

A \$35,000 APDA grant in 2003 resulted in collecting the data needed by Christine Sapienza, PhD, and Bari Hoffman-Ruddy, PhD, to apply for and receive funding from the National Institutes of Health/National Center for Medical Rehabilitation Research two years later. That research has resulted in a new tool to help improve swallowing and breathing problems in advanced PD.

The Breather® is a training device that strengthens the expiratory muscles used in swallowing and combats the slowed-down, rigid and weak musculature associated with the disease. The technique also strengthens the muscles used in breathing.

Dr. Sapienza recently concluded a clinical trial test-

ing of the device with 48 patients at the University of Florida, Gainesville. The study's conclusion indicated that the patients who received the intervention using expiratory muscle-strength training demonstrated improvement in their ability to swallow and breathe.

Some of the treatment goals when using The Breather® are to optimize lung power, improve cardiovascular endurance, clear phlegm from the airway and improve voice and swallowing.

Patients are advised to discuss the use of this new tool with a licensed speech and language pathologist.

Additional information is available at the Web site www.pnmedical.com. ■

Sharon Kha Leads Arizona Chapter with Laughter

Sharon Kha knows Parkinson's disease first hand.



Sharon belts out a song during her "Parkinson's Rap" show.

Her father, a Mennonite missionary, was diagnosed with the disease in 1982 and died of a stroke eight years later. She was diagnosed in 2003 and has been forced to retire from the University of Arizona, where she worked for 22 years and served as associate vice president for communications, directing news services and acting as spokesperson for three presidents. Today she is the leader of APDA's Arizona

Chapter.

Having seen the face of Parkinson's up close, Sharon admits that, "It isn't pretty. I couldn't stop crying for weeks after my diagnosis. I imagined the family feeling about me the way we felt about Dad – worried and then exasperated and exhausted."

But her native intelligence, determination, professional media experience, and sense of humor rose above the depression and she concluded that people can have power over Parkinson's.

When she agreed to become the chapter's president, Sharon's public relations and media instincts kicked in (she was a radio news reporter and TV documentaries producer in Tucson for more than a decade), and she realized that if she wanted to increase awareness, she needed to address groups "who did not need another 'disease' talk." So she created a comedy routine incorporating her explanation of the disease's effects, and has audiences from social-service groups to Parkinson's conferences enthralled.

(See Sharon Kha's "Parkinson's Rap" and "Laughing at Parkinson's" on YouTube.)

In her dialogue are lines such as:

"My biggest, all-time pet peeve is, if we have to have a medication, couldn't they call it L-genius, or L-intelligentia, not L-dopa. Who wants to say, 'I have to take my L-dopa now?'"

"When you go into a room of Parkies (Parkinson's patients), you think you are in a poker

convention. Everyone's trying to bluff everyone with vacant stares."

And in one of her routines, she talks about opening a Parkinson's resort and casino where drinks would be shaken, not stirred; people would go to dyskinesia disco and dance the Michael J. Fox trot; where waitresses go around with trays of Mirapex® and Requip®, and the music would include "Shake, Rattle and Roll," and "Please Help Me I'm Falling."

While laughter is her greatest tool, determination has also helped her to meet the disease head on.

One year after her formal diagnosis she participated in the first competitive athletic event in her life -- riding a tandem bicycle in the 35-mile segment of El Tour de Tucson, a cycling event that attracts 7,000 people. She completed it in two hours and 11 minutes and winning a medal for finishing. But the success was not achieved without months of training with Dr. Becky Farley, an international cycling competitor, and 16 days of intense two-hour-a-day movement and speech therapy with Drs. Farley and Cynthia Fox.

Sharon also serves on three community boards of directors and has become a liturgist in her church. The scores on her Unified Parkinson's Disease Rating Scale have actually improved.

"I'm not so naïve as to think I'm cured, but I do think the quality of my life improved when I started taking charge," she says.

One of her favorite stories is of a man who went to a wise rabbi to ask the most important question in the world: Is there life after death? "That is not the most important question in the world," said the rabbi. "The most important question is, 'Is there life before death?'"

Sharon Kha, who believes in leading with laughter and by example states, most emphatically:

It is possible to take charge of your life, even with Parkinson's.

It is possible for your will to override your brain.

It is possible to have Power Over Parkinson's. ■



In her role of Arizona Chapter president, Sharon accepts a check from Susan Barry, president of Long Cares Foundation, assisted by Mike Deir, former Long Realty employee and retiring member of the chapter board. With them are David Richter, chapter past president, and Barbara McGill, Long Realty agent.

Study Links Constipation to Future PD

A Mayo Clinic study led by professor of neurology and epidemiology Walter A. Rocca, MD, has discovered a history of constipation that is about two times more frequent in a group of men and women having Parkinson's disease (PD) than in an age-matched group not having the disease.

Chronic constipation is common among people with PD, and it has been suggested that it may precede the appearance of classic physical symptoms of the disease in some people. For example, in the Honolulu-Asia Aging Study, men who reported less frequent bowel movements had a significantly higher risk of PD over a study interval of 24 years than men who reported more frequent bowel movements.

Dr. Rocca's team compared nearly 40 years of medical records of 196 men and women who developed PD at an average age of 71 years with a similar age and gender control group who did not have the disease. Approximately 36 percent of the Parkinson's group had a history of constipation compared to 20 percent of the controls. After allowing for differences in age, smoking,

coffee drinking, the use of constipation-inducing drugs, and constipation during the 19 years prior to the onset of PD, Parkinson's patients remained about twice as likely to have a history of constipation.

According to Dr. Rocca, the findings suggest that constipation is an early manifestation of the neurodegenerative process underlying PD and add new evidence to accumulating literature suggesting that PD has a very long preclinical period.

The scientists note, however, that because the digestive ailment is not directly related to the nervous system, constipation can not be considered a specific PD marker, and that more studies are needed to evaluate the link.

APDA's new free supplement "Constipation & Parkinson's Disease," written by Robert Jenco, PharmD, and Mary L. Wagner, PharmD, of the Ernest Mario School of Pharmacy, Rutgers University, New Brunswick, N.J., is available by calling 800-223-2732, or can be downloaded from APDA's Web site, www.apdaparkinson.org. ■

Senate Approves NETPR Bill

The Senate's final approval of the Department of Defense Appropriations bill at the end of 2009 included \$25 million for the innovative Neurotoxin Exposure Treatment Parkinson's Research (NETPR) program. The NETPR program is the only Parkinson's-specific research program funded by the federal government. Advocates must work each year to secure funding for this program, and the Parkinson's community rallied through tough economic times to ensure that the NETPR program did not receive a budget cut. The legislation must now be signed by President Obama. ■

Teva Announces Generic Drug for PD Symptoms

Teva Pharmaceutical has announced the availability of a generic treatment for the signs and symptoms of idiopathic Parkinson's disease.

Pramipexole diHCl tablets are available in 0.125 mg strength, in a bottle size of 63, and 0.25 mg, .05 mg, 1 mg, and 1.5 mg strengths, in bottle sizes of 90.

The new medication is the generic equivalent of Mirapex®. ■



The 16th Parkinson's Unity Walk will take place Sat., April 24 in New York City's Central Park. More than 10,000 people participated in last year's walk raising approximately \$1.5 million for PD research.

Information about the event and registration can be completed online at www.unitywalk.org or by calling 866-PUW-Walk (866-789-9255).

APDA joins the entire American Parkinson's disease community in mourning the loss of the Parkinson's Unity Walk founder, Margot Zobel, who passed away on Jan. 29, 2010.

DAYTIME SLEEPINESS

By Lee W. Tempel, MD

Parkinson's disease (PD) involves changes in the upper brain stem. This area also has to do with wakefulness. As PD progresses there are definite changes that affect one's ability to keep alert. This is a gradual process and at some point a PD patient may have enough of a problem to qualify for the condition of "excessive daytime sleepiness."

There are many other potential causes and they should also be considered. There are a number of medical conditions (sleep disorders of various kinds, diabetes, congestive heart failure, etc.) as well as psychological conditions (anxiety, depression, etc.) that can cause excessive sleepiness or drowsiness as can medications. Some of them can contribute relatively more than others. If medications are questioned as part of the problem, a careful review with your neurologist (and primary physicians for general medications) may be beneficial. In moderate to severe PD, though, a majority of the drowsiness may be just because of the PD. It does tend to worsen over time but not necessarily in a predictable way. Daytime drowsiness is also worsened by any accompanying dementia.

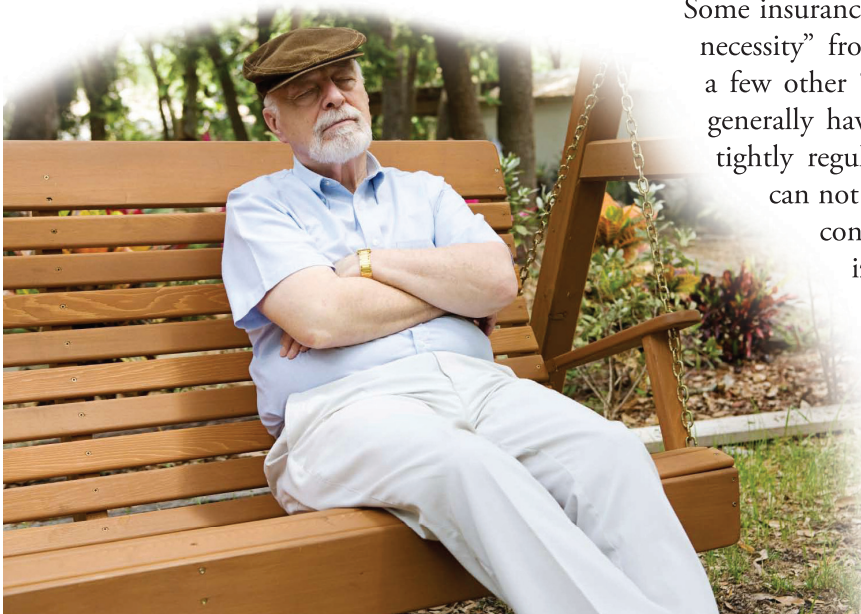
There are some limited options to improve the situation; many of my patients are retired and/or for other reasons are "just sitting around." As we talk, they can recognize that they fall asleep most often when they are not actively engaged in anything. If they nap too much during the day, then they also sometimes start having problems getting to sleep or staying

asleep at night. I encourage them to set a schedule of "things to do" for each day. I don't intend for these to necessarily be physically difficult tasks nor to try to schedule things to take up every minute of every day. Some of those tasks may be everyday necessary "chores" that their spouse or partner may otherwise have to do. But, very importantly, I also encourage patients to think of any active task (watching TV is NOT active!) that is fun, interesting or challenging – something they look forward to doing – and do it. This might be games, computer work, reading, working crossword or other puzzles, or more physically active things according to that patient's ability. It helps to "get moving" and also helps to get out of the house when that is possible. Patients who have no immediate family or close friends are obviously up against a greater challenge.

Finally, there are certain medications that promote wakefulness. These usually are indicated for specific sleep disorders such as narcolepsy, obstructive sleep apnea, or shift wake disorder (people who have drowsiness because they switch from day shifts or vice versa). These medications do not have FDA-approved indications for the more general condition of excessive daytime sleepiness simply by itself nor for the specific condition of drowsiness in association with PD.

Perhaps the most common medication used in such a way is Provigil® (modafinil). Often, because there is not FDA indication for PD-associated drowsiness, insurance companies may not cover the medication. Some insurance carriers require a "letter of medical necessity" from the treating physician. There are a few other "wakefulness" medications, but they generally have more potential for abuse and are tightly regulated. These medications sometimes can not be used depending on other medical conditions. It is also important to realize that these medications are not to "give energy," they are to promote wakefulness. If used, they should be dosed carefully by the prescribing physician. ■

Dr. Tempel is a movement disorders specialist at St. John's Mercy Medical Center, St. Louis.



Educational Material

Most APDA publications can be downloaded free from our Web site, www.apdaparkinson.org, publications page.

The new APDA e-newsletter provides timely news about all aspects of PD and a helpful "Tip of the Month." The newsletter is free, and you can unsubscribe any time. Sign up on the APDA Web site's home page.

Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling 800-223-2732, faxing to 718-981-4399, or contacting any of the APDA Information and Referral Centers throughout the United States.



BOOKLETS

(order by letter)

- A. Parkinson's Disease Handbook
(English, German, Italian, Spanish)
- B. Young Parkinson's Handbook
- C. Be Active
- D. Be Independent
- E. Speaking Effectively
- F. Good Nutrition
- G. Aquatic Exercise for Parkinson's Disease
- H. My Mommy Has PD...But It's Okay!

SUPPLEMENTS

(order by number)

- 4. Keys to Caregiving
- 5. Hospitalization of a Parkinson's Patient
- 6. The Living Will and Durable Power of Attorney for Health Care

- 7. Parkinson's Disease and Oral Health
- 8. The Family Unit and Parkinson's
- 10. The Challenge of Parkinson's Disease: Adapting to a Nursing Home
- 13. Medical Management of Parkinson's Disease and Medications Approved for Use in the USA
- 16. When Should Parkinson's Disease Patients Go to the Emergency Room?
- 17. Neuro-ophthalmology and PD
- 20. Fatigue in Parkinson's
- 21. Dr. Andrew Weil's Recommendations for Healthy Aging
- 22. Depression and Parkinson's
- 23. Incontinence and Parkinson's
- 24. Employment and Parkinson's
- 25. Constipation and Parkinson's

FLYERS

- Basic Information about Parkinson's Disease
- National Young Onset Center
- Medications to Be Avoided or Used with Caution in PD
- 34 Helpful Hints to Improve the Quality of Life of People with Parkinson's

WEB SITES

- www.apdaparkinson.org
- www.youngparkinsons.org
- www.apdawest.org

DVD

- Managing Parkinson's Straight Talk and Honest Hope, Second Edition

Materials concerning research in the field of Parkinson's disease, and answers to readers' questions are solely for the information of the reader and should not be used for treatment purposes, but rather as a source for discussion with the patient's health provider.

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