



# The American Parkinson Disease Association

W I N T E R 2 0 0 7 N E W S L E T T E R

## The American Parkinson Disease Association

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## PARKINSON'S DISEASE IN THE YOUNG

By Michael Rezak, MD, PhD

Medical Director, APDA Young Onset I&R Center, Glenview, Ill.

It is difficult to receive the diagnosis of Parkinson's disease (PD) at any age, but to develop this chronic, neurodegenerative disease at a younger age is particularly challenging. While the neuropathology and most clinical symptoms are the same at whatever age PD develops, the psychological, social and medical management implications are very different in the young-onset category of PD. Despite varying estimates, it is believed that approximately 10 percent of all people with PD fall into the young-onset variety, defined as occurring between the ages of 21 and 50. Although both environmental and genetic causes for PD in this age group have been implicated, it appears genetics may play a greater role in this group than in those with older age of onset.

Special attention must be paid to the effects of PD on the family in young-onset PD. In this group individuals are just beginning families and children are of school age. This is the time of life when family activities begin and financial growth occurs. The stress of dealing with a chronic disease is difficult and can take its toll on intrafamilial relationships.

Added to this is the frequent accompaniment of depression, anxiety and sexual dysfunction that can result in a chaotic situation that often requires intervention in the form of psychotherapy and counseling in order to preserve the family unit. The need to remain open to psychological counseling should be kept in mind, since timely intervention may be the key to preventing a disastrous out-

come for the family.

Counseling regarding long term financial planning is also essential for the younger patient with a slowly progressive, chronic disease. The need to provide financially for the daily requirements of a young family at a time when it is most needed is a major stress for the patient and spouse. Consideration of setting aside funds for future goals needs to be addressed (e.g., college tuition etc.) as early as possible. The high cost of medical care for the long term also requires planning to optimize insurance benefits and to be aware of the resources and options that are available, such as HMO, VA benefits, worker's compensation and Social Security disability. Finding reputable professionals such as insurance agents and financial planners with whom these issues can be discussed may certainly relieve much anxiety.

The medical management of the young-onset Parkinson's patient requires an understanding of the greater tendency of this group to develop dyskinesias (most commonly dystonia) and motor fluctuations when taking levodopa.

It is interesting to note that unlike the older onset PD patient, dystonic contractions of a focal area of the body (commonly the foot) may actually be the main complaint of the young person with Parkinson's. It therefore becomes mandatory to employ all levodopa-sparing strategies at our disposal when attempting to treat symptoms in the young PD patient. This includes the use of MAO-B inhibitors, anticholinergics, amantadine and dopamine receptor ago-

## Rotigotine Patches for Treatment of Early-Stage Parkinson's Disease.

A multi-center, randomized, double-blind study was designed to evaluate the safety and efficacy of the dopamine agonist rotigotine, supplied via a once daily skin patch versus placebo in patients with early-stage PD. The lead investigator of the study, Ray L. Watts, MD, concluded that rotigotine, administered a dose of 6mg per day, was effective in the treatment of early-stage PD. In addition, rotigotine appeared to be well-tolerated by patients. ■

### APDA Is America's Largest Grass Roots PD Organization

APDA is the country's largest grass roots organization serving the Parkinson's community. It is a 501(c)(3) not-for-profit organization and receives no governmental or public funding. Each year APDA contributes more than \$3 million for research and more than \$3 million for direct patient and caregiver support through the generous support of individual and corporate donations. You can be a partner in easing the burden and finding a cure with a tax-deductible gift to the American Parkinson Disease Association, Inc. Call 1-800-223-2732 for details. ■

Dear Reader:

APDA is 46 years old this year and has been a funding partner in every scientific breakthrough since its 1961 inception. A proud achievement, though I like to think that each year is our last year in meeting half our mission to "...Find the Cure."

Recently the Robert Wood Johnson Medical School created the Roger C. Duvoisin, MD

Visiting Professorship in Movement Disorders. Dr. Duvoisin, a pioneer in establishing genetic factors in PD, served as our Scientific Advisory Board (SAB) chairman for many years. He was succeeded by Dr. G.

Frederick Wooten of the University of Virginia, who was named the first Duvoisin Visiting Professor.

And, when I read about new findings in one of our centers for advanced research, hope of curing this disease is sparked anew. In recent days there have been important findings reported from the University of Virginia, the University of Alabama and Emory University. Just yesterday, I read of a new discovery about genetic mutation at the Mayo Clinic/Jacksonville, where a member of our SAB is a leading researcher. It is good to know that our efforts and contributions are supporting the work of America's finest scientists.

Past successes and future promises in research are satisfying, but it is our mission's first half, to "Ease the

Burden..." that I would like everyone to think about.

There is an accepted premise in fund-raising circles that it is easier to raise funds for research than for patient support. Patient and caregiver support, however, is as vital an objective as research for APDA. Adding our 60th Information & Referral Center at

the Dartmouth-Hitchcock Medical Center in New Hampshire recently was a proud achievement because each center brings support and strength to hundreds of people in that area.

Our network of centers across the United States is also the core to establishing and maintaining almost a thousand support groups, which serve

as educational and social resources for patients and their caregivers. These services--plus programs, retreats, referral services and a library of free educational materials -- are all part of APDA's unique dual mission.

So, while scientific breakthroughs get the headlines, let us remember that those with PD and their caregivers begin each day challenged beyond any of our imaginations, and be equally proud that your contributions are easing their burdens until a cure is found.



Vincent N. Gattullo  
President



# A NEW FRAMELESS APPROACH TO DEEP BRAIN STIMULATION

By Kathryn L. Holloway, MD, Associate Professor, McGuire Veteran's Affairs - Medical Center, Richmond, Va.

Miriam L. Hirsch, MS, RN, Neurosurgical Nurse Coordinator, Virginia Commonwealth University Medical Center, Richmond, Va.

In approximately 75 percent of people with Parkinson's disease, (PD) the medications used to control symptoms become less effective with time. Some patients may experience too little or too much movement. Others may not respond at all to the medications and/or may develop neuropsychiatric complications. When the regimen of available medications and the various rehabilitation strategies become less effective in managing symptoms, surgical intervention can be considered.

The deep brain stimulation (DBS) is a relatively new surgical intervention used to treat movement disorders such as essential tremor, Parkinson's disease and dystonia. It was approved by the Food and Drug Administration to treat essential tremor and tremor in PD in July, 1997 and to treat advanced motor symptoms in PD in January, 2002.

The subthalamic nucleus and the globus pallidus (GPi) are two locations in the brain that are targeted in the DBS procedure for the treatment of Parkinson's disease. DBS administers a well-controlled electrical current into the targeted area(s). This electrical current functions as an "off switch" by disrupting brain signals responsible for the abnormal physical movement. This disruption helps restore more normal activity in the brain thus enabling more controlled movement. DBS does not involve destruction of brain tissue, and its effects are adjustable and reversible.

It is preferred to thalamotomy or pallidotomy, two surgical techniques that involve the actual destruction of the brain cells that are "misfiring".

The effectiveness of the DBS procedure depends on accurate placement of the brain lead(s). Electrical impulses generated from an implanted package pass through the lead to the targeted area. The targeted areas or nuclei are quite small, approximately the size of a grape, however, the optimal area is approximately the size of a grain of rice! Special imaging techniques and the placement of a metal, stereotactic head frame on the patient's skull guide the positioning of the leads. Certain areas of the brain generate a characteristic sound. Microelectrode recording (MER) is conducted during surgery and involves "listening" to the brain cells to identify these specific areas. The patient is awake during the surgery and becomes an important member of the team in determining whether ben-

eficial effects occur when the stimulation is applied during surgery.

DBS surgery is time-consuming, usually lasting three to six hours per side of the brain. The most common complaints from patients include back and neck pain and fatigue. These complaints occasionally can become so disabling that the patient has a difficult time participating in the surgery and/or requests to have the surgery stopped. The traditional approach to DBS surgery involves attaching a large, metal halo device to the patient's skull and securing it to the surgical table. The frame's effectiveness has been proven during several decades of use, however, the negative aspects of the frame are that it creates complete immobilization of the patient's head and neck and it obscures the patient's line of vision.

In an effort to simplify the DBS procedure and to enable greater patient comfort and participation during surgery, neurosurgeons at Virginia Commonwealth University and Cleveland Clinic worked with Image Guided Neurologics Inc. to develop a frameless stereotactic technique. The heavy frame has been replaced with the NexFrame, a disposable guidance device. This new device does not require that the head and neck be kept in a fixed position and the patient can move or adjust his/her position if needed. Most importantly, the accuracy of the frameless and framed techniques has been found to be equal. (J.Neurosurg/ Volume 103/September, 2005). ■

## Seven Centers for Advanced Research

APDA provides approximately \$1 million annually to its eight centers for advanced research at Emory University School of Medicine, Atlanta, Ga.; UMDNJ-Robert Wood Johnson Medical School, New Brunswick, N.J.; Boston University School of Medicine, Boston, Mass.; University of Virginia Medical Center, Charlottesville, Va.; UCLA School of Medicine, Los Angeles, Cal.; Washington University Medical Center, St. Louis, Mo.; the University of Pittsburgh and the University of Alabama at Birmingham, Ala. In addition, more than \$ 2 million is awarded to individual scientists in the form of fellowships and research grants. ■

# Questions & Answers

Enrico Fazzini, DO, PhD

Assoc. Prof. Neurology New York University, New York, NY,  
University of Nevada, Las Vegas, NV,  
N.Y. Institute of Technology, Old Westbury, NY.

**Q:** I was diagnosed with PD five years ago. I am having problems with my eye staying open and just recently with freezing. My PD doctor gave me a pill for my eyes but I do not feel they are helping. The pill is Pyridostigmine BR 60 mg. and I take one four times a day. I have been on this medication for about two months. Can you tell me what the doctor can do for my freezing and is this a progression of the disease? I will appreciate any answers you can give me.

**A:** In terms of your blinking, you may be having blepharospasm -- a condition in which your eyelid muscles spasm causing your eyes to clamp shut. This can be treated with Botox. Freezing can occur when your medications are not working ("off") or when your medications are working too much as demonstrated by the accompanying presence of mild dyskinesia ("on"). You must find a medication schedule that allows the minimization of "on/off" fluctuations. If nothing else works then bilateral subthalamic deep brain stimulation may help.

**Q:** I am a 34 year old woman who has not officially been diagnosed with Parkinson's; however, I currently have a constant tremor, difficulty speaking and walking. To date the only non-daily medication that has been consistently effective is an injection of estrogen, two types of testosterone and B-12 on a bi-weekly basis. This relieves my symptoms of tremor for approximately two

weeks. Has hormone therapy ever been studied for treatment of Parkinson's patients? Any information would be helpful in helping me understand my symptoms.

**A:** There are no studies to suggest that hormone therapy helps to treat Parkinson's disease.

**Q:** I am staying with a lady who has Parkinson's disease, and I would like to find out what to feed her and not to feed her. Is there food that interacts with her medication? She is currently taking carbidopa/levodopa and lorazepam. Could you please send me some helpful information?

**A:** Proteins interfere with the absorption of levodopa. Carbohydrates help levodopa to be absorbed into the body. Levodopa is absorbed from the small intestine. Therefore, take levodopa one hour before a low protein, high carbohydrate breakfast and lunch and one hour before a moderate protein and carbohydrate dinner. Lunch, in particular, is the meal that makes or breaks how the patient performs in the afternoon. If the patient takes levodopa with or right after a high-protein lunch, the medication will not work and the patient will be slow the rest of the day.

**Q:** I have PD, and I have constipation as well. I would like to know what can be taken to get rid of this problem. Second question is about my speaking so people can hear me. Do you have something that will take care of both problems?

**A:** Eat lots of fruits, vegetables, salads and cereals and drink as much water as you can. Take Colace® and Senokot® every day regardless of whether you have a bowel movement. If there is no bowel movement on the second day, take an oral laxative and use a glycerin suppository. If there is still no bowel movement by the third day, you must try an enema. If this is not successful, you must scoop out the stool from the rectum using a plastic glove and vaseline and then retry the enema. These suggestions should be approved by your personal physician before being implemented.

**Q:** What is the value of saving umbilical cord blood for future treatment of PD? Is there research being done?

**A:** The cells derived from umbilical cord blood do have the genetic ability to produce dopamine and may be a source of tissue for transplantation in the future.

**Q:** My mother was diagnosed with multiple sclerosis many years ago and has been battling it ever since. She has since seen a new neurologist and was diagnosed with the beginning stages of Parkinson's. Is that possible? Can you have both? She is also taking meds for Alzheimers, as well.

**A:** The disorders are in no way related. However, I have seen patients with Multiple Sclerosis and Parkinson's disease. ■

## A Brooklyn Deli "Art Gallery" Raises Funds to Battle PD

### Take this quiz.

What would you expect to buy in a Brooklyn (NY) deli?

- a. Kosher dill pickles
- b. Pastrami sandwiches on rye
- c. Original art
- d. All of the above
- e. None of the above

If the deli is TJs Sammitch Shoppe and Deli at 2756 Gerritsen Ave., Gerritsen Beach, Brooklyn, the correct answer is d., all of the above.

Original art for sale in a deli? Yep, and Tom Mitchell, (as in SamMITCH) donates all the proceeds to APDA. His latest sale was a portrait of Ronald Regan.

Tom, who was diagnosed with PD in 2002 at age 42, calls his art-lined shop the "Cheers" of Gerritsen Beach and proves it, as regulars drop in and everybody knows their names.

But how did a nice Irish Catholic boy and accounting/religious studies Manhattan College graduate from the Bronx become a Brooklyn deli owner with an Italian-Jewish angel named Sheryl Cohen for a manager? It has been a long road for such a young man. And, buoyed by his recent deep brain stimulation (DBS) surgery success, he says, "I'm simply not done yet. I have a long way to go."

After 16 years as an accountant with a major New York utility, Tom worked in the same capacity, plus human resources, for a small medical-supply company. That is

continues to add to his deli gallery that includes 75 paintings.

"I'm a religious person," he says, and admits that when he first heard his diagnosis, "I was mad at God. So I had a long talk with Him, and He told me if I would carry His cross (PD), and show other people how to cope with life's 'downers,' He would take me down a fascinating road, and so far, He hasn't let me down."

Now the accountant turned author, artist, sportsman, deli man believes the best is still ahead. ■



*Mixed media means paintings and ham on a roll to artist/Parkinson's patient Tom Mitchell in his Brooklyn gallery/deli.*

*Tom and his manager, Sheryl Cohen, pose outside the "Cheers" of Gerritsen Beach.*

when the entrepreneurial bug bit, and he knew he wanted to own his own business.

He always liked cooking and was certainly a "people person," so when the deli became available, he bit, hired Sheryl, who in addition to food management does well with renovation such as painting, and gutted the store, adding a counter. When he had to be out for the DBS surgery, she filled in.

Tom says that his diagnosis has opened his eyes. "I take time to smell the roses now." He continues to golf and coach a local sports program. He's written a book dedicated to his daughter, Rose, I'm Cold Put On A Sweater, published by Author House, and is working on another. And he

### No Public Support

APDA receives no government or other public funds and is entirely dependent upon contributions from businesses, foundations, but mostly, from individuals. Gifts can be made by mail, telephone, fax or e-mail:

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Welcome to new coordinators around the country: **Jennifer Newsome**, BSN Birmingham, Ala.; **Diane Church, PhD.**, at the new center at Dartmouth-Hitchcock Medical Center, Lebanon, N.H.; **Mary Birch Fenn**, BSN, Albany, NY; **Mary Ellen Hickman**, RN, Staten Island, N.Y.; **Mary Ellen Tribodeao**, Warwick, R.I.; and **Misty Hall**, Memphis, Tenn.

## In the Northeast

The **Massachusetts** Chapter is introducing “New Resource and Networking Parkinson’s Support Group” for people with PD, caregivers, family and friends. Nancy Mazoneson (781-693-5069) has information about the group and its first meeting, March 1, at the Waltham Jewish Family & Children’s Service.

*Correction: The New England Regional Symposium reported in the last issue was held in Sturbridge, Mass., not in Maine.*

## In the South

It’s called the “Sixth Annual Young-Onset Parkinson’s Disease Retreat,” but the name hardly tells the story. A casualty of the Gulf Coast hurricanes, the annual event refused to be a washout and was postponed, rescheduled, relocated, rearranged, but now it is back with a bang! Presented by APDA’s **Mississippi, Tennessee, Louisiana, Alabama, Iowa** and **Florida** I&R centers, this year’s schedule includes four days of lectures, events, discussions, socials and recreation for patients and families at the University of Southern Mississippi’s Gulf coast Research Lab in Ocean Springs, Miss. Brenda Allred, RN, who is coordinating the event with Caryn Crenshaw, RN, bills it as a retreat for the young-onset and the young at heart as well.

## In the West



*Los Angeles Chapter members Linda Behar, Veena Goel, Janice Feder, Mark Siegel, Madeline Field, Bunni Dybnis and Kathy Artosis enjoying a brunch at the Friar's Club.*



*San Diego Chapter president Dr. Ron Kabayashi, right, presents a check to Scientific Advisory Board member Dr. Evan Snyder for his research at the Burnham Institute.*

**Orange County’s** Chapter and I&R Center benefited from being a designated charity of the Long Beach International City Bank Marathon last fall. In addition to the \$12,345 proceeds, the group had the distinction of authors John Ball, Living Well, Running Hard (Lessons Learned from Living with Parkinson’s Disease) and Evan Henry, Shaker Guy, participating on their behalf.



*Orange County's 5K race team is ready for a successful run.*

The Greater **Los Angeles** Chapter makes money even when it isn’t trying. The famous LA Friar’s Club was the setting for the Chapter’s Holiday Brunch in December. Though not designated a fund-raiser, the event brought \$6,000 to the Greater LA Chapter’s coffers.

## In the Southwest

Two eminent experts on movement disorder will participate in the “Power Over Parkinson’s” conference in Tucson, Ariz. on March 8. Neuropsychologist Paul Nussbaum, PhD, will discuss “Brain Health” at the morning session, and neurologist Dr. William Marks, will be the afternoon speaker. Information is available at [www.azapda.org](http://www.azapda.org) or by calling 520-326-5400. ■

# 2006 Walk-a-thons Raise Big \$\$s for Research

APDA chapters across the country walked home more than a quarter million dollars for scientific research last year. Thirty-four walk-a-thons from Rhode Island to Washington netted more than \$353,000. All walk-a-thon funds are donated to APDA's scientific research program, which last year awarded \$3.3 million to centers for advanced research and individual researchers. The Midwest Chapter's Riverwalk netted more than \$50,000 in September, followed by San Diego's May walk, which netted \$38,177, an increase of more than \$10,000 from its 2005 event. Third place was claimed by Central Maryland Parkinson Outreach Chapter, which conducted two

walks totaling \$36,615. Other walks that resulted in double-



*Minnesota's walk was as much fun as it was successful.*

digit contributions were: Massachusetts (\$30,223); Connecticut (\$25,323); Nebraska (\$23,753); the Dr. John Brady Walk in Waxahachie, Texas (\$19,876); Greater Los Angeles (\$17,404); Tampa Bay Movers & Shakers (\$17,275); Wisconsin (\$15,488); Minnesota (\$14,286) and South Florida (\$13,781).

The "grand-daddy" of all walks is the annual Unity Walk in New York City's Central Park. This year's will be on April 28, and is expected to surpass 2006's \$1.3 million, which benefitted the major PD organizations. Several APDA teams attend the event, which last year numbered 10,000 participants from across the United States. ■

## An Open Mind Proves to be the First Step to Brain Surgery

*This is not a clinical story of how deep brain stimulation (DBS) is performed or what happens. It is the story of one woman's journey in opening her mind and heart to a procedure that she felt could buy her more time until there is a cure for PD. Deb Wityk of Redfield, Iowa, was diagnosed in June 1995, at age 42, and in October 2006 started a DBS procedure.*

In October 2004, I was without a neurologist and in search of another, bringing me to Dr. Lynn K. Struck in December that year. At our first meeting she asked if I had considered DBS for possible symptom relief. My immediate thought was, "Why should I let a doctor drill holes in my head and hot-wire my brain?"

When attending the World Parkinson Congress last year, I avoided the sessions addressing DBS. I was not open to that information. Yet, through-

out the Congress I continually had conversations with individuals who had undergone the procedure and had positive results.

After 10 years on Sinemet, my dyskinesias became more debilitating and I entered a drug study. The drug proved unsuccessful for me, and I was discouraged and in need of hope. Then in June, I attended an annual seminar in West Des Moines at which Dr. Struck introduced two patients who discussed their positive results after DBS.

That did it! I contacted Dr. Struck's office to say yes to DBS. I was always cheering for others to consider different ideas or to be open to change in their life. It was time for me to do the same!

After surgical and psychological evaluations, the date was set for Oct. 3,

2006, and it was time to prepare. I reached out to my family, friends and support group, who expressed hesitation and fear for my welfare. But realizing that I had made my decision to proceed, they embraced me with their love and prayers.

I was informed of the surgery, risks and benefits. I was honest about my anxiety, sense of humor and easiness to cry. I listened to people's concerns but in the end did what I needed to do for myself. In my visualization, the outcome was to be great.

The first phase took place Oct. 2 in Omaha. Having been off my meds for 12 hours, I was cramped, stiff and rigid. Then I was able to move my fingers and felt my body relax without drugs. It felt wonderful! I cried with joy at the miracle. Nine days later a second surgery connected the leads and placed the power pack. I

*cont. on pg. 8*

## An Open Mind Proves to be the First Step to Brain Surgery *cont. from page 7*

was on my way to being bionic. How does a person go from a closed mind about a procedure to lying awake as a drill makes a hole in her head? The power of prayer and openness to what is best for me. To under-

stand that to continue to do what I love and to be there for my family, I said "yes" to DBS. And as my fortune cookie from a recent Chinese meal said so well, "Everyone around you is rooting for you. Don't give up!"

*(Des Moines I&R Center I&R Coordinator, Sam Erwin, who shared this story with us, reports that Deb is doing well.)*

*Dr. Struck is the Des Moines I&R Center Medical Director. ■*

## Being in the Dog House Can Have Its Benefits

*Dog bites man - no news.*

*Man bites dog - news*

*Man and dog help each other - good news.*

The dog did not achieve recognition as man's best friend for nothing. Now *canis domesticus* can add the honorary title of APDA's best friend. Here are just a few samples of recent events where Fido and friends got top billing:



*Grandalf gives coordinator Faye Kerns a big welcoming kiss.*

and Conference Center included talks on music therapy, and therapeutic and recreational horseback riding. Wisconsin coordinator Jessica Hahn also included The Wonderful Animals Giving Support (WAGS) Pet Therapy of Kentucky, a service-dog company in its April walk-a-thon.



*Bonnie Millen, who works at a Long Island nursing home, displays the Paws for Parkinson's T-shirt she and Willow won at the Long Island dog walk.*

In **New York** it was all dogs as Long Island coordinators Eileen Giannetti and Julie Garofalo took the annual dog walk to new heights with a "Howl-o-ween" Walk Oct. 22. Radio and print media clamored to photograph and interview the adorable pooches, and the Long Island Chapter raised more than \$8,000 for PD research.

**St. Louis** coordinator Jan Meyer fea-

tured Razzle, a C.H.A.M.P. (Canine Helpers Allow More Possibilities) Assistance Dogs, Inc. graduate which earned his way into Bob Thomas's home and heart in a recent publication. Razzle, a home-service dog, picks up objects from the floor, fetches a special emergency phone if Bob says "911," and shows his appreciation of his master's organ playing with a cocked head and wagging tail. ■



*Bob and Razzle share home, hearth and a big easy chair*

### \$30 Million to Research and Growing

APDA has contributed nearly \$30 million to PD research, including the 1987 study at Robert Wood Johnson Medical School, which discovered the alpha-synuclein protein, central to the pathogenesis of the disease. Contributions can be restricted to research or other APDA programs. Contact us at APDA, 1-800-223-2732.

# ADVANCES IN PARKINSON'S MEDICATION

By Dee E. Silver, MD, Medical Director of the Parkinson's Disease Association of San Diego and Director of the APDA I&R Center in San Diego, Cal.

There are many new drugs now available for the treatment of idiopathic Parkinson's disease (PD). Careful thought has to be given to the various drugs, their use, and the order in which they are started and added. The guiding principle is evidence-based: does the drug reduce rigidity, tremor, and akinesia, and does it improve activities of daily living and quality of life? Evidence-based data are obtained through double-blind placebo controlled clinical trials. There must be awareness whether the drug does or does not reduce "off" time and increase "on" time, compared to placebo.

Two new drugs have recently been released in the United States. They are Azilect® (rasagiline) and Zelapar® (selegiline HCl).

Azilect is a new second-generation MAO-B inhibitor. Its metabolite is Azilect-aminoiodan, which is not an amphetamine. The drug is given once a day in tablets of 0.5 and 1.0 mg. In tissue-cultures study and in animal models, it has shown to be neuroprotective.

There have been three large clinical trials with this drug. The first trial was TEMPO, a monotherapy trial for newly-diagnosed PD patients. Azilect was given over six months. It improved the United PD Rating Scale (UPDRS) scores by four points over placebo, with few adverse side effects. At six months, the placebo group was given Azilect (medication was switched from placebo to Azilect) and compared to those patients initially on Azilect. The earlier-treated Azilect group always remained better than the placebo group. This could possibly indicate disease modification. At two years, 46 percent of patients who were in the study remained adequately controlled on Azilect. After six years, the early Azilect started group had less progression as compared to the delayed start group.

A second study, called PRESTO, was an adjunctive therapy trial. All patients were optimized carbidopa/levodopa treated patients. Many were on dopamine agonists. Placebo was compared to 0.5 mg and 1 mg of active medication. The 0.5 mg patients had a half hour less of "off" time and the 1 mg group had one hour less of "off" time.

LARGO, the third trial, showed that entacapone and Azilect were similar in reducing "off" time, which was 0.8 hours less "off" time in optimized carbidopa/levodopa treated patients. Freezing of the gait was also improved.

There have now been well over a thousand patients who have been on Azilect for up to seven years. I have

about 20 patients who have been on Azilect for more than six months, and they appear to be doing quite well.

Significant reduction of "off" time for patients on carbidopa/levodopa is seen using Azilect and many of these patients have been on dopamine agonists.

Adverse effects compared to placebo were abnormal dreams, and several other minor side effects. There will probably be a tyramine warning (i.e. cheeses, red wines, etc.) when using this drug. There may be concerns with the use of Selective Serotonin Uptake Inhibitors (SSRI) and antidepressants.

Zelapar (selegiline HCl), a MAO-B inhibitor, is an orally-disintegrating tablet that has been compared to placebo in clinical trials. It is given once a day and has fewer amphetamine metabolites than oral selegiline. Selegiline previously (in the DATATOP study) has been shown to delay L-dopa therapy for nine months and to give some symptomatic benefit. Zelapar has been shown to reduce "off" time by 1.6 hours compared to placebo.

There is an increase in dyskinesia-free "on" time by 1.4 hours over placebo. Titration of Zelapar from 1.25 mg to 2.5 mg occurs in six weeks. Most adverse effects occur in the first six weeks and they may include dizziness, dyspepsia, hallucinations, headaches, dyskinesias, and nausea. Eighty per cent of patients did not reduce their dose of L-dopa, but 20% were able to reduce the dose by 50 to 60 mg. There will probably not be a tyramine warning. There may be concerns with the use of SSRIs and antidepressants.

Parkinson's patients with or without medication may have compulsive and/or impulsive reward seeking behavior, such as overeating, excessive spending, shopping, computer use, and gambling.

Exelon®, an acetylcholine esterase inhibitor, has now been shown to improve dementia in PD patients and it has an FDA approval for its treatment. It improves cognition, activities of daily living, and quality of life, and may improve some aspects of behavior and neuropsychiatric symptoms. The caregivers' impressions supported the clinical improvements suggested by the clinical trials. ■

*The above article was adapted from the one originally published in the November-December 2006 issue of Parkinson Post, the newsletter of the Parkinson's Disease Association of San Diego.*

# MASSAGE AND PARKINSON'S DISEASE

As Parkinson's symptoms involve rigidity, bradykinesia and tremors, it's no wonder that many experience some form of back pain. One theory is that flexor muscles are stronger than extensor muscles and therefore cause posture to stoop and result in lower back strain. Another theory is that Parkinson's patients do not have the ability to recover or relax their muscles and over time can suffer from some form of musculo-skeletal discomfort. While research clearly documents the benefits of conventional treatments prescribed by physical therapists, massage therapy also can be beneficial in improving musculo-skeletal discomfort.

Some benefits of massage include:

- **Stress Reduction.** It is well known that stress creates an exacerbation in Parkinson's symptoms.
- **Muscle Flexibility Improvement.** It relieves muscle rigidity and stiffness that often leads to muscle exhaustion.
- **Increase in Circulation.** Blood supply improves nutrition to muscles, speeding up the elimination of metabolic wastes which can offer muscles some reprieve from the contractions.
- **Sleep Improvement.** Results in regular bowel movements and enhances the effectiveness of medication.

There are many different types of massage techniques which can prove helpful with circulatory and musculoskeletal benefits. Here are just a few common types:

## Swedish massage:

This is the most common. Swedish massage is very soothing using oil and smooth strokes.

## Deep tissue therapies:

Also known as neuromuscular

trigger point and Rolfing often are a bit more rigorous yet produce effective results with chronic pain. Eastern styles work with the body's meridian pathways and focus to regulate the flow of energy in the body. This type of massage is given through finger pressure, rocking and stretching such as: Acupressure, Thai or Shiatsu.

Some tips to consider when looking for a massage therapist are:

- Make sure that he/she has graduated from an accredited school and is li-



censed and certified. This will guarantee a level of professionalism and competence in anatomy, physiology and different massage techniques for considering your individual benefit.

- Inquire if they are members of the American Massage Therapy Association, the Association Bodywork and Massage Professionals, or a similar well-known professional organization. This type of membership guarantees that they maintain continuing education credentials as required by licensure.

- Check with your health care provider. Some insurance carriers are recognizing the medical therapeutic benefits. If you are not covered through your health insurance, expect to pay a fee somewhere between \$30-\$60 for an hour.

- Understand that this is not just a form of luxury; massage therapy can be considered regular health maintenance, and increases quality of life.

- Consult your health care provider to discuss if massage is right for you. As these benefits are demonstrated in clinical research studies, physicians will advocate the use of therapeutic massage more widely, thus incorporating them into customary medical practice.

For more information on therapeutic massage and to find a therapist in your area consult the following websites:

[www.ncbtmb.com](http://www.ncbtmb.com)

This is the home page for the National Certification Board for Therapeutic Massage and Bodywork. The information on this website is geared towards professionals, but it does have a link to locate national certified practitioners in your area.

[www.massagetherapy.com/learnmore](http://www.massagetherapy.com/learnmore)

This site is run by the American Bodywork and Massage Professionals, which is a professional association for many types of bodyworkers including massage therapists. The site contains introductory information about massage and the resources necessary to find ABMP certified massage therapists in your area.

[www.massagetherapy.org](http://www.massagetherapy.org)

This is the homepage of the American Massage Therapy Association. The American Massage Therapy Association is well-respected professional organization for massage therapists. The site is a resource to find therapists in your area. ■

*This article was adapted from "Knead a Massage" published in the Spring 2006 issue of Parkinson's Page, the newsletter of the Maine APDA I&R Center in Falmouth, Maine.*

# DISCLOSING THE DIAGNOSIS OF PARKINSON'S DISEASE

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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 upfront 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-of-attorney, 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](http://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](http://www.eeoc.gov)

Toll-free: 1-800-669-4000

8 am - 8pm (ET)

Social Security Administration

Web site: [www.ssa.gov](http://www.ssa.gov)

Toll-free 1-800-772-1213

7am- 7pm, Mon-Fri ■

## PRESCRIPTIONS COVERAGE

More than 45 million Americans are without health insurance. This lack of insurance affects people from different ethnic groups and socioeconomic backgrounds.

For people without prescription coverage, it can be difficult to know where to find help. The Partnership for Prescription Assistance (PPA) is a pharmaceutical industry sponsored service that offers a single point of access to more than 475 patient assistance programs including over 180 programs offered by pharmaceutical companies.

It can be researched by calling 1-888-4PPA-NOW or visiting [www.pparx.org](http://www.pparx.org)

# Information on Parkinson's Disease

Single copies of the following publications may be obtained free of charge by writing to the national APDA office or by calling the toll-free number 1-800-223-2732 or faxing to 1-718-981-4399, or contacting any of the 60 APDA Information and Referral Centers.

## EDUCATIONAL BOOKLETS

1. **Basic Information about Parkinson's Disease**  
4-page brochure (English, Chinese, Spanish)
2. **Parkinson's Disease Handbook**  
Symptoms, causes, treatment; 40-page booklet (English, German, Italian, Portuguese, Spanish, Russian)
3. **Be Active** - A suggested exercise program for people with Parkinson's disease; 25-page booklet (English, German, Italian)
4. **Be Independent** - Equipment and suggestions for daily living activities; 32-page booklet (English, German, Italian, Spanish)
5. **Speaking Effectively** - Speech and swallowing problems in Parkinson's disease; 34-page booklet (English, Japanese)
6. **Good Nutrition** - 20-page booklet (English), new edition
7. **Young Parkinson's Handbook** - 78-page booklet (English)
8. **How to Start a Parkinson's Disease Support Group** - 24-page booklet (English, Italian)
9. **Aquatic Exercise for Parkinson's Disease** - 20-page booklet (English) for patients and their families
10. **Next Step After your Diagnosis** - 23-page booklet (English) Finding Information and Support
11. **My Mommy Has PD... But It's Okay!** - 20-page booklet for young children.

## EDUCATIONAL SUPPLEMENTS

Caring for the Caregiver: Body, Mind and Spirit; The Family Unit; The Fine Art of "Recreation & Socialization" with PD; Medical Management of PD; Vision Problems and PD; Mirapex® in the Treatment of PD; Fatigue in Parkinson's Disease; Healthy Aging.

## DVD

**Managing Parkinson's** - Straight Talk and Honest Hope.

Created by the Washington State Chapter of APDA especially for newly diagnosed Parkinson's patients and their loved ones. Leading experts explain what PD is and how it is treated, how to deal with symptoms of the disease, some of the medications' side-effects and how to keep a positive outlook in dealing with it.

## APDA WORLDWIDE WEB SITE

[www.apdaparkinson.org](http://www.apdaparkinson.org) for PD I&R Centers, Chapters, Support Groups, education and information material, meeting dates, publications, medical abstracts, clinical trials and research application guidelines.

## WORLD PARKINSON DISEASE ASSOCIATION WEB SITE

[www.wpda.org](http://www.wpda.org). A weekly updated source of world news.

## Parkinson's Disease In The Young

*cont. from page 1*

nists for more potent, symptomatic treatment. Often these drugs are used in combination to achieve an optimal benefit without inducing side effects. Nevertheless, levodopa, the most efficacious drug in all PD patients, should be used at the lowest doses possible when an inadequate response is obtained with other medications or when side effects are encountered at doses necessary to achieve a desirable response. Recent data has shown that young-onset PD patients have a more slowly progression course and seem to have a smoother course than their older counterparts. Cognitive problems seem to be decreased in this group as well. Finally, deep brain stimulation, when necessary, seems to provide a more robust response in the younger PD age group.

When seeking neurological care it is in the patient's best interest to seek a physician who has an understanding of the unique requirements of the young PD patient. This usually means a neurologist who subspecializes in Movement Disorders. Having someone who has this knowledge base as the treating physician will maximize long term control of symptoms while minimizing complications of treatment which ultimately translates into long-term maintenance of functional independence.

Those affected by PD at younger ages comprise a special group. When attention is paid to the many important issues that may arise over the many years of living with this disease, long term psychological and medical health can be maximized. ■

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*Materials concerning the 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.*