

The Parkinson's Bulletin

March-May 2009

Special Conference Edition



Spring 2009

ROBERT WOOD JOHNSON
UNIVERSITY HOSPITAL

The NJ/APDA Parkinson Disease
Information and Referral Center

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Dopamine Agonists vs. Levodopa in PD Treatment: Do You Feel Like a Ping Pong?

Dr. Lawrence Golbe, Professor of Neurology, UMDNJ-RWJMS

You've heard that the "modern" way to treat the loss of dopamine-producing brain cells of PD is to stimulate the dopamine receptors on the surviving cells by taking pramipexole (Mirapex) or ropinirole (Requip). On the other hand, you've heard that directly replacing dopamine by taking the older drug levodopa avoids the sleepiness that agonists can cause. Then you hear about the involuntary movements of levodopa. Then you hear about the hallucinations of the dopamine agonists, the short action of levodopa, the compulsive behavior of the agonists, the theory that levodopa can accelerate the degenerative process of PD.

Soon after the discovery in the late 1950s that PD involved a loss of dopamine-producing brain cells, someone thought of giving dopamine as a medication. Actually, dopamine itself cannot enter the brain from the blood, so they gave levodopa, a chemical that does enter the brain, where it is converted to dopamine. Levodopa – combined with carbidopa to suppress the nausea that plain levodopa usually causes – entered the market in 1968 and remains the most powerful drug available for PD. But is it always the best?

Around 1970, it became clear that patients with more advanced PD, within a few months after starting levodopa, often

experienced non-rhythmic involuntary writhing movements, typically at the lips, neck, shoulders and trunk. Furthermore, the duration of benefit from each dose of levodopa would progressively shorten as the underlying PD advanced, requiring dosing as often as every two or three hours in some cases. Some of those frequent doses had no effect at all, a phenomenon called "dose failure."

It should be emphasized that the likelihood of these complications increases with more advanced PD and not with greater duration of levodopa treatment. So, patients who were in the early stages of PD when levodopa became available did not develop those complications for years, while those who were already in the advanced stages developed them within a few months.

To remedy these levodopa-related problems, drug companies adapted a chemical called ergot, a natural compound made by certain fungi and known for centuries as a cause of mass poisonings from spoilage of stored grain. The resulting synthetic compounds are called dopamine agonists because they directly stimulate some of the dopamine receptors. These are the docking stations on the healthy brain cells that receive information from the degenerating dopamine-producing brain cells.

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Spring Annual Conference
Saturday,
April 4, 2009
Register today!

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Coordinator's Corner
Elizabeth Schaaf,
NJ APDA Parkinson Disease
Information and Referral Center

Dear Friends,

We are excited to announce a fundraiser and social event, Strike Out Parkinson's Bowl-a-thon on Sunday, March 22, 3:00 pm to 5:30 pm at the Brunswick Zone (Carolier Lanes) in North Brunswick, NJ. We hope you can join us. For a \$40.00 minimum donation per person ; you will receive two games of bowling, rental of shoes and refreshments. Registration and payment is due by Thursday, March 12, 2009. You can register as an individual or you can register as a team of up to six people.

On Saturday, April 4, our annual symposium, *Living Well with Parkinson's* will be held at a new location, The Imperia in Somerset, NJ. Please see program details on page 13 and registration information on page 6.

Our next telephone support groups series for people with Parkinson's (PWP) and caregivers will begin on Monday, March 23. Please see page 12 for registration details. This support group takes place in the comfort of your own home!

Our Painting with Parkinson's series for PWP and their caregivers, friends and family will begin in May; please see pages 12 and 14. Don't miss this fun class! No prior painting experience needed.

On April 25, the Unity Walk will take place in Central Park in New York City. If you are interested in forming a team, please call the Unity Walk at **1-866-789-9255**. The NJ Chapter APDA, with the support of the Parkinson's Unity Walk will take a bus to the walk. Space is very limited; registration and payment are required Please see page 7 to register today!

I hope to see you at our upcoming events!

Kind Regards,

Elizabeth Schaaf, Coordinator

Coordinator, NJ APDA Information & Referral Center

Elizabeth.schaaf@rwjuh.edu

"Material presented in this newsletter is solely for information of the reader. It is not intended for treatment purposes, but rather for discussion with the patient's physician."

**BRAIN & MIND
FITNESS TRAINING**

*for adults age 50 & over with
Parkinson's Disease*

RUTGERS UNIVERSITY

is offering a state-of-the-art class that provides intensive one-on-one practice on basic and complex mental abilities, and teaches skills for improving negative moods.

The class is offered as part of research, there is no cost to you.
Class meets for five 90-minute sessions and five 2-hour sessions at your convenience, and is taught by advanced graduate students in psychology.
No medications involved.

**PLEASE CALL US
FOR MORE INFO!
RUTGERS AGING LAB,
(732) 445-1413**



NJ Support Group Spotlight

**Lawrenceville PD Support Group
Upcoming Meetings**

Wed., Apr. 15, 2009

Speaker: Steve Goerlich
Find the Best Medical Equipment for the Least \$\$:
Navigating Medicare

Wed., May 20, 2009

Cynthia Sharp, Esq. of Sharp Bratton Attorneys:
Elder Law: Estate Planning and Asset Protection
**Meetings are from 1:00 pm to 3:00 pm at the
Lawrenceville Presbyterian Church**

**If you plan to attend, contact John Wicoff at
jrwicoff@verizon.net**

***For a listing of all of the support groups in
NJ, please call (732) 745-7520.***

President's Notes

**NJ Chapter
American Parkinson Disease Association
Benton Yip**

Dear Readers:

The New Jersey American Parkinson Disease Association presents several events and co-sponsors other events that will bring you and your family opportunities to learn about Parkinson's, meet new people, share ideas, and help make a difference.

We are pleased to announce an inaugural bowling fundraising event will be held at Brunswick Zone - Carolier Lanes on Sunday, March 22. The week before this event, please try joining us in Washington, D.C., March 15-17, 2009. for a meeting with our elected representatives to advocate funding for PD research programs and stem cell research. Please reach out to the Parkinson's Action Network in Washington DC if you are interested in attending. In April, we have our very informative People with Parkinson's and Family educational conference at The Imperia in Somerset, NJ. This is the NJ APDA Information & Research Center and chapter's flagship event held every year. Adding to this momentum, in April, we hope you attend the Parkinson's Unity Walk in Central Park. Please remember that every month, support groups throughout the state have speakers or exercise activities for you to stay active: mind, body and spirit. Do you want dance lessons? Tai-chi lessons? Guitar? Become active with us or a support group and help make it happen by getting friends to attend the fundraisers and make phone calls.

On a different note, I want to introduce and welcome, Vicki Collier, our new NJ APDA treasurer. Vicki brings new insight and fresh approaches to our chapter. I want to thank Nikki Taussig for her guidance and strength in the many years she has served as our treasurer and her diligence in maintaining records for two administrations. Nikki brought to us stability and professionalism when she initially took over the role seven years ago. She will be missed.

I hope to see you in 2009 Good Health and Good Spirits!

Sincerely,

Benton Yip, President of NJ APDA

Njapda@gmail.com
www.njapda.org



**New Jersey Home
Show:
Parkinson's Exhibit
Volunteers Needed**

**March 6, 7 and 8, 2009
Please call Peter Buckley at
732-499-7140.**

A Study of Insomnia in Patients with PD

We invite PD patients who are suffering from sleep problems to find out more about this research study.

You must be between the ages of
35-85 years old.

By volunteering to be a participant
you will be providing valuable
information to our understanding
of effective treatments for this
disorder.

**Please call us at:
1-877-795-4673**



**To Make A Donation to the
NJ American Parkinson Disease Association
Please Make Checks Payable to:**

**NJ APDA
Mail to: PO Box 2026
Edison NJ 08818**

Continued from page 1

The first dopamine agonist, bromocriptine, became available in the late 1970s. In the US, one other ergot-derived agonist, pergolide (Permax) has since become available, as have the non-ergot agonists, pramipexole (Mirapex), ropinirole (Requip) and rotigotine (Neupro patch). These drugs avoided most of the dose-related fluctuations and involuntary "dyskinesia" caused by levodopa in the more advanced patients. An additional agonist, apomorphine (Apokyn), is available only by injection and is useful in quickly ending a prolonged "off" period, but lasts for less than an hour.

The two oldest agonists, bromocriptine and pergolide, have been taken off the market because of side effects and the rotigotine patch has been withdrawn because of technical difficulties with the patch itself.

Starting in the early 1980s, a hypothesis developed among neuroscientists that levodopa may accelerate the loss of dopamine-producing brain cells in PD. This was prompted by the observation that toxic chemicals called free radicals are produced as a byproduct of the body's breakdown of dopamine. Dopamine brain cells are especially sensitive to these. The dopamine agonists do not produce free radicals, however, a selling point heavily emphasized by their manufacturers. This hypothesis made its way into the lectures and writing of neurologists, especially those who received funding from those drug companies, and even into the newsletters of national PD organizations that received such funding.

The widespread negative publicity about levodopa led many physicians and patients to avoid that drug, even preferring to tolerate loss of their jobs to avoid accelerating their PD. The hypothesis was slowly disproven by around 2000. However, the notion of "levodopa sparing" still appears in advertising for the agonists.

Still, the agonists offer the advantages over levodopa of less frequent dosing, at least for more advanced patients. While both agonists and levodopa can be used on a twice-a-day schedule in early-stage patients, later in the illness the symptoms typically require three doses of agonists or as many as six or seven of levodopa.

Another undisputed advantage of the agonists over levodopa is their far lower incidence, again in the advanced patients, to cause dyskinesia. This is particularly relevant for those whose PD began before age 55.

On the other side of the coin are two important side effects of the agonists that are less common with levodopa. The first is psychosis. This typically takes the form of seeing friendly or beloved people or animals that are not actually there. The person realizes the

error immediately, but this does not banish the visitor. Only rarely is the hallucination threatening. There can also be delusions, where the patient harbors an erroneous belief. This occurs mainly in those who are over 70 or have some degree of dementia.

The other common agonist side effect that is less common but still important with levodopa is sleepiness. This can be socially disabling and can even occur while driving.

The agonists can have some additional side effects that occur very rarely, if at all, with levodopa. The most important is compulsive behavior, the most common manifestation of which is gambling. The patient may lose thousands on lottery tickets, trips to Atlantic City or to Web gambling sites before the family realizes that it's a medical problem. Other compulsions seen with agonists include shopping, eating or sexual activity.

Another agonist side effect in a few patients is swelling, redness and pain in the hands or feet, typically on the side more affected by the PD itself. This can be difficult to distinguish from thrombophlebitis or arthritis and can take months to disappear after the agonist is discontinued.

As important as the side effects is the consistent observation in controlled trials that the agonists are not as powerful as levodopa at controlling the slowness and stiffness of PD. However, for patients in the earlier stages, the agonists' efficacy is adequate.

The usual practice among movement disorders specialists these days is to use the agonists as first-line PD treatment only in patients who are younger than about 55 and have no cognitive difficulties or important medical problems. These are the patients most likely to have dyskinesias from levodopa and least likely to have hallucinations from agonists.

For patients older than about 65, levodopa is generally the better choice, and for people between 55 and 65, a complicated decision that takes all of these issues into account must be made by the neurologist together with the patient and family.

The next few years will bring forms of levodopa that last longer and, by entering the brain more slowly, avoid much of the dyskinesia. There will also be new agonists that hope to reduce the side effects of that class of drug. My advice is to ask whether your sources of information on the new drugs stand to profit, either financially or professionally, from having you follow their advice.

(In case you were wondering, I do not receive any sort of fees or research funding from manufacturers of the drugs mentioned in this article.) ##

Anxiety and Parkinson's Disease

Karina L. Bienfait, PhD

Department of Psychiatry, UMDNJ- Robert Wood Johnson Medical School

Although motor symptoms such as tremor, rigidity and slowness of movement are the characteristic features of Parkinson's disease (PD), non-motor symptoms, including anxiety, depression, insomnia and cognitive difficulties, are also extremely prevalent aspects of PD. While these symptoms may occur after one is diagnosed, research has shown that anxiety, in addition to depression, is often present even before the development of motor symptoms. In fact, it has been suggested that anxiety itself may be a risk factor for the later development of PD, or may even be an early sign of the disease.

How common is it and what are the symptoms?

It is estimated that approximately 25% to 75% of patients with PD have some signs of anxiety. Symptoms may include excessive and/or uncontrollable worry, restlessness, fatigue, difficulty concentrating, sleeping problems, and increased muscle tension. The presence of anxiety may also worsen motor symptoms of PD, especially tremor.

Why is anxiety important in PD?

Anxiety can cause great distress for individuals with PD and their families. In addition to its impact on worsening motor symptoms, anxiety has been found to negatively effect quality of life in patients with PD. Specifically, PD patients with anxiety have reported greater disability and a lowered sense of physical and emotional well-being than those without anxiety. Given these deleterious effects, it is important for anxiety to be accurately diagnosed and treated in PD.

How is anxiety identified in PD?

Anxiety often goes undiagnosed in patients with PD. Because some of the symptoms of anxiety overlap with the symptoms of PD, anxiety may be overlooked by both physicians and patients. Despite this, anxiety can be detected by the presence of excessive or uncontrollable worries in addition to some of the overlapping symptoms, such as fatigue, restlessness, difficulty concentrating and/or sleeping problems. As mentioned above, many PD patients will also report being lifelong worriers and may find that the worry has increased since the development of PD. The presence of depression may also indicate the presence of anxiety, as the two commonly co-occur.

How can anxiety be treated in PD?

Several options are available to treat anxiety in PD. Anti-anxiety medications and certain antidepressants may be prescribed, but as with any medication, may not be tolerated by all patients. Non-pharmacological approaches, such as cognitive-behavioral therapy (CBT), are also available.

CBT is a type of talk therapy that teaches people with PD specific skills, such as relaxation training, to use on a daily basis to cope with feelings of anxiety and depression. CBT may be a beneficial treatment option for PD patients who have side effects to, do not want to take, or have not found adequate relief with anti-anxiety and antidepressant medications.

How can I find out more information?

For additional information about anxiety, depression and CBT treatment resources in the community, contact Dr. Bienfait at 732-235-4160, or consult your local physician.

Depression and Social Support in Parkinson's Disease (PD) ***A study for PD patients and their families funded by the National Institutes of Health (NIH)***

Do you have PD and suffer from these symptoms?

- ◆ *Getting more and more isolated*
- ◆ *Feel sad or empty most of the day*
- ◆ *Difficulty falling asleep or staying asleep*
- ◆ *Loss of interest in daily activities*
 - ◆ *Unable to concentrate*
 - ◆ *Feeling tired all of the time*

HELP US FIND ANSWERS

Dr. Roseanne Dobkin at the Robert Wood Johnson Medical School in New Jersey is conducting a 10-week treatment study of depression in PD. **The study treatment does not involve medication** and helps people to change thinking patterns and behaviors that may be related to depression.

All research care including an extensive psychiatric evaluation is provided at no cost to those who qualify. A friend, family member, or significant other will also be asked to participate in the study. *Participants are paid \$20.00 for each study evaluation.*

**For more information, please call
Dr. Dobkin at:
732- 235-4051**



*Parkinson Conference
for People with Parkinson's and Their Families
Saturday, April 4, 2009*

*9:30 am to 3:15 pm
The Imperia, Somerset, NJ*

*Please send to : NJ APDA I & R Center, 120 Albany Street, Suite 360,
New Brunswick, NJ 08901*

*Space is limited; please register by returning completed form and payment
no later than Monday, March 23, 2009.*

You will receive confirmation and directions to The Imperia once you register.

REGISTRATION FORM

Please print

Name (s) : Please circle one

_____	Menu selection: Chicken Francoise	Filet of Sole	Eggplant Parmesan
_____	Menu selection: Chicken Francoise	Filet of Sole	Eggplant Parmesan
_____	Menu selection: Chicken Francoise	Filet of Sole	Eggplant Parmesan
_____	Menu selection: Chicken Francoise	Filet of Sole	Eggplant Parmesan

Address to send confirmation letter:

Email _____ Phone (daytime) _____

Amount enclosed (\$25.00 per person) _____

Nursing Professionals (\$35.00 per person) with Nursing Continuing Education Credits _____
Continuing Education Credits have been applied for through Robert Wood Johnson University Hospital, an approved provider of continuing nursing education by NJSNA, an accredited approver, by the American Nurses Credentialing Center's Commission on Accreditation.

If you are a support group leader or co-facilitator, please check here _____ YES

How Long have you been overseeing or assisting the group? _____

Your Name _____ Group name/location _____

*Checks made payable to the NJ APDA Parkinson I & R Center
Subject: Spring PD Conference-April 4*



Bus Available To Take Walkers To The Unity Walk!

Saturday, April 25, 2009

Thanks to the support of the NJ American Parkinson Disease Association Chapter, we will take a bus to the Unity Walk for Parkinson's disease in Central Park on Saturday, April 25, 2009. We hope you will join us! For more information on the walk itself, please call (1-866-789-9255) or go to <http://www.unitywalk.org>. Booths open at 10:00 am ; program starts at 12:00 pm; walk begins at 1:00 pm. The bus will leave NYC by 3:15 pm. **Please note that seats can not be held without registration (below) and payment. Space is limited. Register today!**

Please bring a bagged lunch with you; only snacks and water will be provided on the bus.

BUS Routes

Sears

Back Parking Lot
New Brunswick NJ 08902
Departs at 8:15 am

Robert Wood Johnson-Rahway

865 Stone St.
Rahway, NJ 07065
Departs at 9:00 am

Mountainside Hospital

1 Bay Ave,
Montclair, NJ 07402
Departs at 9:45 am

For more information, please call (732) 745-7520.

Space is limited; please send in your registration form and payment.

Spaces can not held without payment.

Unity Walk Bus Registration

**Please complete and send to: NJ APDA Parkinson I & R Center
120 Albany Street, Suite 360, New Brunswick, New Jersey 08901
(732) 745-7520 (office)**

Name (s) _____

Address _____

Phone (daytime) _____ Cell phone (for day of event-must have) _____

Email _____

Amount Enclosed (\$13.00 Per Person-includes tip for driver) _____

Please make checks payable to the NJ Chapter, APDA

Departing from (please circle one) Bus Route

1. Sears-New Brunswick

2. RWJUH @ Rahway

3. Mountainside Hospital



Tai Chi Ch'uan as exercise for Parkinson's Disease

David C. King, PT, MS

Kessler Institute for Rehabilitation

Tai Chi Ch'uan is best known as a slow rhythmic martial art often practiced for health reasons. Certainly most of us have seen pictures of groups of people practicing together in parks in China. There have recently been several studies completed to lend evidence of how it can help people with Parkinson's Disease.

Origins of Tai Chi as exercise

No one knows for certain the origin of Tai Chi. One legend has its roots being developed by the surgeon Hua To in A.D. 300. He studied animal behavior for clues to health and longevity and developed a series of movements based on his studies called "The Frolics of the Five Animals" (tiger, deer, monkey, bear, bird).

By A.D. 700 the movements had linked into one continuous pattern resulting in a deepening of the performer's concentration and strength. Some postures in the "form" retain animal names today (Phoenix flaps its wings, Grasp the sparrow's tail).

As pressures from invaders attempting to seize Chinese land mounted emperors maintained standing armies but monks in temples had to protect themselves against attacks by bandits. Monasteries combined martial training with training to learn control of their body, mind and spirit; trained their Ch'i ("the vital energy underpinning every living thing").

About A.D. 1100 Chang San-Feng, a Taoist monk, encountered a crane fighting with a snake. The crane jabbed with his beak in straight angular strikes, the snake avoided these by changing his shape and position (staying soft and resilient) and then counter attacking while the bird was completing his thrust. Chang San-Feng reasoned that it would be possible for a weaker opponent to overcome a stronger one if he became soft and resilient. He incorporated this lesson into a new, softer version of a martial art.

Today several different styles of Tai Chi exist. These styles are named for the family that developed it. In America the most popular style is the Yang style and is best known in its slow rhythmic style but a faster style also exists.

Research demonstrates Tai Chi's effectiveness

In 1996 the National Institute on Aging studied Tai Chi by having 24 relatively inactive, older (most were over 70) people living in the community participate in a 15 week training program of weekly Tai Chi classes. Tai Chi was

found to reduce the risk of multiple falls by 47.5% and participants cited less fear of falling versus participants who had been assigned to other exercises.

To support the idea of a "Tai Chi Buddy Program" researchers asked 8 people with Parkinson's Disease (PWP) and 7 of their care partners with no history of PD to participate in 12 weekly sessions of 45 minutes each. 6 of the 8 PWPs and all of the care partners reported perceiving a physical benefit. Improved balance was reported most often with other physical, psychosocial and social benefits also cited. This study suggests that care partners can also benefit if they participate in the Tai Chi classes with the PWP.

Comparing people who exercise with Tai Chi to people who don't exercise at all; 33 PWP were randomly assigned to a Tai Chi group or a control (no exercise training) group. The Tai Chi group participated in 20 one-hour long "classes" within 10-13 weeks. The Tai Chi group improved more than the control group in 6 of 8 measures of gait and balance. All Tai Chi participants reported satisfaction with the program and improvements in well-being.

How to get into Tai Chi

Tai Chi can usually be found in or near your community. You may find "studios" in the yellow pages or you will probably find it at many local health and community organizations (YMCA, YMHA, JCC, etc.). People who teach Tai Chi are particularly well known for their caring and patience with their students and you will most likely find it to be a supportive experience.

Tai Chi does not have to be performed while standing. If you are afraid of falling while practicing Tai Chi, most instructors will make accommodations for you to learn while seated and the benefits of increased weight shift and fluidity of motion learned in the chair may help you to eventually feel safe participating while standing.

If performed in a pool, the fear of falling while practicing Tai Chi is removed and the individual can relax and enjoy the benefits while being supported by the water. In water, heart rate and blood pressure are reduced and the phenomenon of "freezing" with Parkinson's is rarely, if ever, seen. People who exercise with Tai Chi say that they feel more able to move, safer while standing and walking and report improvements in mood and ability to socialize. If these improvements sound worthwhile please try to find a local class (or organize one) today. ##



Asset Protections and the Parkinson's Disease Community

By: John J. Ross, Attorney at Law, Freehold, NJ

Few events are more devastating to families than the placement of a loved one in a nursing home or other long-term care facility. Most of us like to think that we would never even consider placing a parent, spouse, brother, sister or child in a long-term care facility. For families affected by Parkinson's disease, preparing for such a possibility is something that must be considered.

Regrettably, conditions such as Parkinson's Disease can rob people of their ability to care for themselves. Sometimes, the care that the person needs cannot be provided by family members. Accordingly, various legal and financial issues must be addressed, such as:

Can I afford to pay for the necessary care?

Will providing the necessary care cause me to lose my home and/or most of my life's savings?

Are there legal ways of preserving assets for the spouse who remains at home or for other family members while providing the necessary care?

When these and other questions relating to long-term care arise, a family needs clear and accurate guidance to ensure that personal tragedy is not followed by financial devastation. This article will attempt to acquaint members of the Parkinson's Disease Community with key concepts related to long-term care planning and examples of strategies used to shelter assets without compromising the Parkinson's patient's care.

Long Term Care Insurance

A funding source for long-term care is long-term care insurance. Unfortunately, if a person does not already have such insurance in place prior to being diagnosed with Parkinson's disease, he or she will not be able to be approved for such coverage subsequent to receiving such a diagnosis. Therefore, the focus of this article will be on another source of funding, Medicaid, and ways that Medicaid eligibility can be secured while preserving assets for one's family.

Medicaid and Not Medicare

It warrants emphasis that the program that can provide long-term financial assistance to a person who must reside in an assisted living facility or nursing home is Medicaid and not Medicare. At most, Medicare may

pay for all or part of care in a nursing home for no more than one hundred (100) days. Medicaid can pay a person's care costs in a nursing home or assisted living facility for the balance of a person's life. Another meaningful distinction is that a person can be eligible for Medicare regardless of the amount of his or her income or the value of his or her assets. The Medicaid program has strict income and assets limitations.

The amount of assets that a person is allowed to have in order to qualify for Medicaid depends upon whether the person is married or unmarried. An unmarried individual is allowed to have assets worth no more than \$2,000 if his or her monthly income is \$1,911 or less. If the unmarried individual's monthly income is more than \$1,911, he or she may own assets worth up to \$4,000.

If the Medicaid applicant has a spouse who is still living outside of a nursing home or assisted living facility, additional allowances are made for the spouse. First, Medicaid allows a spouse who remains at home to keep certain assets regardless of their value. For example, the value of a home and its contents, one automobile and personal property are deemed to be exempt and, are not subject to any dollar limit. Second, the spouse is allowed to keep a portion of the non-exempt assets, principally savings and investments, in excess of the \$2,000 or \$4,000 amount allocated to the person who is looking to be approved for Medicaid. How much the Ahealthy@ spouse is allowed to keep depends upon the value of the combined assets of the husband and wife as of the first day of the first month that the husband or wife ceases to live at home. Based upon Medicaid regulations in effect for 2008, if a husband with Parkinson's disease leaves his home and begins residing in a nursing home on February 15, 2009, Medicaid will first determine the value of the combined non-exempt assets as of February 1, 2009. Medicaid then divides the February 1, total by 2, but caps that amount at \$104,400. The product of this calculation represents what Medicaid allows the healthy spouse to keep. For example, if the combined assets are worth \$300,000 on February 1, 2009, the procedure outlined above would be applied as follows:

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$\$300,000 \text{ divided by } 2 = \$150,000.$

\$150,000 is subject to the \$104,400 maximum, so Medicaid would allow the healthy spouse to keep \$104,400. If, on the other hand, the February 1 total is only 100,000, the allowance would be calculated as follows:

$\$100,000 \text{ divided by } 2 = \$50,000.$ \$50,000 is within the \$104,400 maximum, so Medicaid would allow the healthy spouse to keep \$50,000.

One of the goals of long-term care planning is to increase the amount of the assets that will be available to the person who needs Medicaid and his or her family above the limits discussed above.

Medicaid Transfer Penalties and Required Waiting Periods

Most transfers that are made as part of the Medicaid sheltering process must take into consideration the Medicaid penalty that the transfers will trigger. The Medicaid penalty is the period of time for which a person will be ineligible for Medicaid as a result of transfers into a trust made within sixty (60) months of the date of the submission of an application. The penalty or disqualification period is determined by dividing the dollar amount of the asset that is transferred by 6,942, the Medicaid penalty divisor. For example, in the case of a \$100,000 transfer, the penalty would be calculated as follows:

$\$100,000 \text{ divided by } 6,942 = 14.4$

14.4 represents the number of months for which the person would be disqualified from receiving Medicaid if a Medicaid application is submitted within 60 months of the transfer of \$100,000. If the amount transferred is \$400,000, the penalty would be calculated as follows:

$\$400,000 \text{ divided by } 6,942 = 57.62$

57.62 represents the number of months for which the person would be disqualified from receiving Medicaid if a Medicaid application is submitted within 60 months of the transfer of \$400,000.

If a person believes that there is a reasonable chance that all of a significant portion of a 60 month period will elapse following the date a contemplated transfers, a strategy could involve transferring assets that the person desires to protect and waiting until at least 60 months plus one day pass before submitting an application for Medicaid benefits. Such transfers can be made by gifts to trusted individuals or to a trust.

Gift-Giving Versus Trusts

Gift-giving, as a means of divesting assets, is effective, relatively simple and, as a consequence, initially appealing. However, simple and effective is not always best for the person who transfers his or her assets because gift-giving is inherently risky. When gifts are made, not only does a person bear the risk that a gift recipient, could use the assets that have been gifted for his or her own purposes, but the gift-giver is also exposed to risks beyond the trust-worthiness or lack thereof of the gift-recipient. Specifically, in addition to the fact that gifts to individuals can be spent by an individual for his or her own purposes, the gifted assets will also be vulnerable to claims of creditors, divorce actions or a gift-recipient's own death or disability.

An alternative to gifting that can provide a higher level of security is the creation and funding of an irrevocable trust that allows distributions to be made to the client's family members or friend. A properly structured trust can reduce or eliminate the risks associated with gifts and provide some tax advantages. Trust assets can be insulated from claims of creditors, an estranged spouse or the other third party risks which accompany gifts. As a means of reducing the risk of self-dealing by an individual trustee, the trust should require the consent of a co-trustee or other person prior to the distribution of principal. Please note that the trustee can be anybody whom the client chooses (except the client and his or her spouse) including a son, daughter, sibling or other friends or family members. Similarly, the person or persons who would be entitled to receive distributions from the trust can be anybody whom the client chooses, except the client and his or her spouse.

The succeeding section discusses sheltering options that do not generate any disqualification period and can be utilized if a person can not expect to wait 60 months before submitting an application for Medicaid.

Purchase of a Home or Other Exempt Assets

As indicated previously, the home of the spouse who remains in the community is exempt from the Medicaid resource limitation regardless of the value of the home. In this regard, if a couple does not own a home or wishes to upgrade to a more expensive home, assets can be protected by investing assets into a home. For example, I recently worked with a husband whose wife experienced a sudden stroke, as a

Continued on page 11

Continued from page 10

result of which the wife must permanently reside in a nursing home. The husband and wife lived in a mobile home worth less than \$10,000, and owned savings and investments worth approximately \$300,000. The combined amount of savings and investments that the family was allowed to keep was \$106,400. Upon my advice, the husband used approximately \$210,000 to purchase a townhouse which became the husband's new primary (and exempt) residence. Following the purchase, the countable assets consisted of \$90,000 in savings and investments and the mobile home. Accordingly, the countable assets were reduced to less than the \$106,400 maximum, and the wife was financially eligible for Medicaid, effective the month following the completion of the purchase of the townhouse.

Purchase of An Irrevocable Annuity or Promissory Note

Another option that has recently met with success involves using assets in excess of \$106,400 to purchase an irrevocable annuity. Current law appears to exempt an annuity that complies with the following guidelines from the Medicaid resource limitations:

- The annuity must be (a) irrevocable and non-assignable;
- (b) actuarially sound;
- (c) payable in equal installments during the term of the annuity;
- (d) name the State of New Jersey as the remainder beneficiary (upon the death of both of you) for at least the total amount of medical assistance paid on behalf of the Medicaid recipient.

For example, if the annuity is going to be purchased by an eighty (80) year old man, Medicaid requires the annuity to be paid out to the man over the course of no more that 7.31 years due to the fact that Medicaid has adopted a mortality table that says that an 80 year old male has a life expectancy of 7.31 years. Following the purchase of the annuity, the annuity should be viewed as a stream of income and no longer an asset that is counted against the Medicaid resource allowance of an individual or a couple. Since the monthly payments that are payable under the annuity represent a fair exchange for the funds used to purchase the annuity, no disqualification period will be imposed as a result of purchasing the annuity. #



**Painting
For Peace of Mind
Painting Series**

**Join us for this fun and
interactive art series with
Sandy Frank, Senior Advisor
and artist, Elena Tuero**


**Fridays, May 1, 8 and 22, 2009
1:00 PM to 3:00 PM**

**Robert Wood Johnson
University Hospital**

**No prior painting experience
needed!**

**Fee: \$35.00
includes painting supplies**

**Please register by April 17, 2009
(see below)**



**Parkinson Disease
Clinical Trials**

Do you want to learn
more about current trials for
Parkinson's disease?

Go to www.pdtrials.org

Painting Series Registration Form

Name (s) _____

Address _____

Phone _____

Email _____

Amount enclosed _____

**Please return to the NJ APDA Parkinson Infor-
mation and Referral Center, 120 Albany Street,
New Brunswick, NJ 08901; please call
(732) 745-7520 with any questions. Checks made
payable to:
NJ APDA I & R Center
Subject-Spring Art Classes**



Upcoming Educational Events and Support Group Meetings Spring 2009-March-May

RWJUH PD Support Groups

Afternoon PD Support Group

Location: RWJUH, New Brunswick
12:30 pm to 2:30 pm. Hospital Auditorium

Thursday, March 19, 2009

Topic: Ask the Advanced Practice Nurse about PD Management

Speaker: Debbie Caputo, APN, UMDNJ-RWJMS

Thursday, April 16, 2009

Offsite Luncheon at Houlihan's
Please call for more information;

11:30 am to 2:00 pm (different time)

Thursday, May 21, 2009

Topic: Speech Swallowing and
Speaker: Karen Davis, MS, CCC-SLP
Speech Therapist, RWJUH



Evening Support Group

Location: RWJUH, New Brunswick
7:00 pm to 9:00 pm Hospital Auditorium
Wednesday, March 20, 2009

Topic: Ask the Nurse Practitioner about PD
Speaker: Debbie Caputo, APN, UMDNJ-RWJMS

Wednesday, April 15, 2009

Topic: From Therapy to Community: How to Exercise with Parkinson's

Speaker: David King, PT, MS. Physical Therapist
Kessler Institute for Rehabilitation

Wednesday, May 20, 2009

Topic: Speech and Swallowing and PD
Speaker: Karen Davis, MS, CCC-SLP
- Speech Therapist, RWJUH



Parkinson's Phone Support and Information Group for People with Parkinson's and Families

This series conveniently meets over the telephone. It will occur on Monday evenings at **7:30 pm, March 23-April 20**. This is an opportunity to join with other people caring for a loved one with PD and People with PD. Cost is \$25.00. **For more info and to register, call DOROT at (877) 819-9147. Topics include: Parkinson's Disease Research and Treatment Options; Anxiety and Depression and PD; Asset Protection; Speech and Swallowing and PD.**

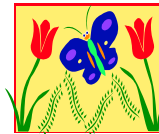


Strike Out Parkinson's Bowl-a-thon!

The NJ American Parkinson Disease Association Chapter will hold a bowl-a-thon on **Sunday, March 22, 2009 at Brunswick Zone (Carolier Lanes) in North Brunswick NJ from 3:00 pm to 5:30 pm**. A minimum \$40.00 donation per person includes bowling, shoe rental, unlimited sodas and light snacks. Join us for fun and camaraderie. Registration deadline is March 12. **See page 14 and 15 for further details. For individual pledge sheets, please go to www.njapda.org or call (732) 745-7520 for any questions.**

Annual Spring Person with Parkinson's and Family Conference

The Spring Annual Symposium for people with Parkinson's (PWP) and caregivers will be held on **Saturday, April 4, 2009, 9:30 am to 3:15 pm** at The Imperia in Somerset, NJ. Fee: \$25.00 per person including continental breakfast and lunch. Space is limited. Please return registration form on page 6 with payment by March 23. Please see program details on page 13.



Bus to the Unity Walk The NJ APDA Chapter will take one bus to the walk to the walk on Saturday, April 25 2009 in NYC. We hope you can join us! The three stops are: Sears in New Brunswick, Robert Wood Johnson University Hospital in Rahway, and Mountainside Hospital in Montclair. Seats are \$13.00 per person which includes driver's tip. Please bring a bag lunch with you. Space is limited! Your registration form and payment will secure your space. **Please see page 7 for registration. Spaces will not be held without payment.**



Painting With Parkinson's For Peace of Mind

Fridays, May 1, 8 and 22, 1:00 pm to 3:00 pm. Join us for this interactive painting class for people with Parkinson's and caregivers. This three week series is \$35.00 per person, which includes guided instruction and all paint materials. **Please call the center at (732) 745-7520 to register. See page 14. Register today!**





*Spring Living Well With
Parkinson's Conference*
Saturday, April 4, 2009
9:30 AM to 3:00 PM

8:30 am to 9:25 am

Registration & Continental Breakfast

9:25 am to 9:35 am

Welcome & Introductions

9:35 am to 10:35 am

Resilience and Parkinson's Disease

Dr. David Rintell, Clinical Psychologist
Brigham and Women's Hospital
Boston, MA

10:35 am to 10:50 am

Break

10:50 am to 11:00 am

Parkinson's Unity Walk

11:00 am to 12:00 pm

Plan For Your Life: Living Well With Parkinson's

Jean Burns and Sheryl Jedlinski
People with Parkinson's and Advocates

12:00 pm to 1:30 pm

Lunch and Presentation of Service Awards

1:45 pm to 2:05 pm

Parkinson's and the Environment

Mona Thiruchelvam, PhD
Assistant Professor,
UMDNJ – Robert Wood Johnson Medical School
Department of Environmental and Occupational
Medicine

2:05 pm to 2:25 pm

Current Treatments and Parkinson's Disease

Fiona Gupta, MD
Movement Disorder Specialist
North Jersey Brain and Spine Center

2:25 pm to 3:00 pm

Questions and Answers



Conference Speakers



Jean Burns and Sheryl

Jedlinski are friends and people with Parkinson's (PWP). They will discuss their website www.pdplan4life.com and share their personal experiences with and triumphs over Parkinson's disease. Sheryl and Jean want to motivate and inspire other people with Parkinson's to take control and make a conscious decision to **LIVE WELL WITH PARKINSON'S**.

Fiona Gupta, MD is a Movement Disorder Specialist practicing in New Jersey. She completed her neurology residency at the University of Connecticut and a fellowship in Movement Disorders at the Mount Sinai School of Medicine in New York City. She will present *Current Management Options for Parkinson's disease (PD)*, including accurate diagnosis, non-pharmacological treatment and current medications used in PD. She will also provide information on surgical treatment and current research being conducted in the field of Parkinson's.

David Rintell, EdD is a clinical psychologist at the Multiple Sclerosis Center at Brigham and Women's Hospital in Boston and at the Metro--west Medical Center in Framingham, Massachusetts, and has a private practice in Brookline, Massachusetts. David will discuss coping techniques and ways to strengthen resilience in people with Parkinson's disease and their caregivers.

Mona Thiruchelvam, PhD is an Assistant Professor of the Environment and Occupational Health Sciences Institute at UMDNJ-Robert Wood Johnson Medical School. She will explain the role of the environment in Parkinson's disease. She will highlight current evidence that implicates the environment in the onset of Parkinson's disease - both risk increasing and risk decreasing factors.

Help Strike Out Parkinson's Bowl-A-Thon 2009

Fundraiser to benefit the
NJ Chapter of the American
Parkinson's Disease Association
Brunswick Zone-Carolier Lanes
790 US Highway 1, North Brunswick, N.J. 08902

Sunday, March 22, 2009 • 3:00 p.m. - 5:30 p.m.

Fee: \$40.00 Minimum Donation per player

Donation includes shoe rentals and refreshments.

Registration forms due by March 12, 2009

Prizes for Top Raising Teams and Individuals!

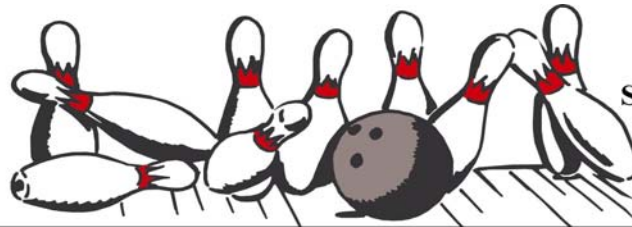
Questions? Please call the NJ APDA Parkinson's Center at (732) 745-7520

www.njapda.org/events



If you are unable to attend the bowl-a-thon but would like to make a donation,
please make check payable to: NJ APDA Chapter and send to NJ APDA I and R Center
120 Albany Street, Suite 360, New Brunswick, NJ 08901

BOWL-A-THON!



Sunday, March 22, 2009



STRIKE OUT PARKINSON'S

Brunswick Zone-Carolier, 790-US Route 1, North Brunswick NJ 08902

Individual/Team Registration Form

Please return by March 12, 2009 to NJ APDA I & R Center, 120 Albany Street, Suite 360, New Brunswick NJ 08901

Team Name if Applicable _____
(please note that there are 6 bowlers per lane, however you may register less than 6 members)

1.	Team Captain's Name	Address	Phone/email	Amount encl.
2.	Bowler's Name	Address	Phone/email	Amount encl.
3.	Bowler's Name	Address	Phone/email	Amount encl.
4.	Bowler's Name	Address	Phone/email	Amount encl.
5.	Bowler's Name	Address	Phone/email	Amount encl.
6.	Bowler's Name	Address	Phone/email	Amount encl.

Please call (732) 745-7520 for individual pledge sheets or go to www.njapda.org/events



15th PARKINSON'S UNITY WALK
COMMUNITY & EDUCATION DAY

FUND THE RESEARCH • FIND THE CURE

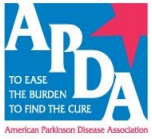
APRIL 25, 2009

**Be Part of the Largest Grassroots
 Fundraising Event in the Country for Parkinson's Disease Research**

- Last year at the 14th Annual Parkinson's Unity Walk, 10,000 people attended in New York City's Central Park ▪ Participants from 50 States and 17 foreign countries came together and raised \$1.8 million for research ▪
- 100% of all donations go towards Parkinson's disease research ▪

FOR MORE INFORMATION

www.unitywalk.org
info@unitywalk.org
 866-PUW-WALK (789-9255)



**New Jersey Parkinson Disease Association
Information & Referral Center**

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Professor of Neurology
Chief, Movement Disorder Clinic
UMDNJ/RWJMS

Medical Director, NJ/APDA
Parkinson Disease Information & Referral
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**American Parkinson Disease
Association**

National Office
Parkinson Plaza
135 Parkinson Avenue
Staten Island, NY 10305-1425
1-800-223-2732

**NJ/APDA Parkinson's Disease
Information and Referral Center**

One RWJ Place, Box 2601
New Brunswick, NJ 08903-2601
(732) 745-7520
(732) 745-3411-fax



**SWIM, Inc.
Accepting Applicants for
Free Water Exercise
Program**

SWIM, Inc., a non profit volunteer organization, is accepting applications for participants in their self directed water exercise program that will be held each Monday at the **Sussex County YMCA from 1:00 pm-3:00 pm.**

Other locations include: Bridgewater, Fanwood/Scotch Plains, Flemington, Madison, Morris/Randolph, and Wildwood Crest, New Jersey.

The program is free to participants. Eligible participant candidates are adults with muscular impairment due to such causes as stroke, MS, accident, MD, arthritis, surgery, Parkinson's, cancer or other causes who find it difficult or impossible to exercise on land. The buoyancy of water provides an environment conducive to movement not possible on land. SWIM, Inc. has been providing this free service at seven other locations in New Jersey since 1975. Information about SWIM, Inc. and locations across the state can be found on their website at <http://www.swim-inc.org>.

Anyone interested in applying should contact *Bob Hopkins*, with SWIM, Inc. at 973-729-3686 or via email at *swimsmart@yahoo.com*.



**Parkinson Bulletin
Change or New Address**

**Please return to NJ APDA Parkinson I & R Center,
120 Albany Street, Suite 360, New Brunswick NJ
08901**

PLEASE PRINT

Name _____

New Address _____

Old Address (if applicable) _____

Phone _____

Email _____