

The Parkinson's Bulletin

December 2007-February 2008



Winter 2007/2008



ROBERT WOOD JOHNSON UNIVERSITY HOSPITAL

*The NJ/APDA Parkinson Disease
Information and Referral Center*
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Support For Walking On A Treadmill

**David King, Physical Therapist, Kessler Rehabilitation Institute and
Robert Wood Johnson University Hospital**

Those of you who know me or have seen one of my presentations on exercise for Parkinson's know that I am a big advocate for walking. Walking has long been called "the best exercise" and John Kennedy during his Presidency advocated every American walk 100-miles. (OK, I only heard about that but, some of you may remember him saying it and actually doing it.)

However, for many people with Parkinson's, there is difficulty walking with a great fear of falling. Because of the dangers of falling, I only advocate walking on a treadmill for the "less involved" people with Parkinson's.

Partial Body Weight Treadmill Training (PBWTT) or walking on a treadmill while supported by a harness is somewhat like hanging in a parachute harness. Early research into using a harness to support a person walking on a treadmill began with spinal cord injured patients and progressed to patients with strokes. Finally a significant number of studies are emerging regarding use of this technique for treating gait problems with Parkinson's.

Miyai, Fujimoto, Uedo, Yamamoto et al. published one of the first studies in the

year 2000. Their research participants walked on treadmills for 4 weeks with up to 20% of their body weight supported. These participants demonstrated increased endurance, increased speed and increased stride length versus a "traditional program of physical therapy." Their overall Parkinson's symptoms were reduced as measured by the United Parkinson's Disease Rating Scale (UPDRS) a scale covering a broad range of Parkinson's symptoms.

Miyai and his group published a second article in the year 2002 demonstrating long term effects of PBWTT. Participants in this study walked on a treadmill with up to 20% body weight support for 45 minutes 3 times per week for one month. They demonstrated long lasting improvement in gait speed and step length versus a control group for 6 months, indicating that the benefits of the exercise may be long lasting.

Looking for an even better way to employ PBWTT in the year 2005 Protas,

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Save the Date!
**Annual Spring
PD Conference**



**Saturday,
March 29,
2008**

**The Pines Manor
Edison, NJ**



*Hello From the Coordinator
Elizabeth Schaaf, NJ APDA
Parkinson Disease
Information & Referral
Center*

Dear Friends:

I hope this newsletter finds you well and enjoying the holiday season.

On Saturday, February 9, 2008, Annie Konopka, 2nd Vice President of the NJ American Parkinson Disease Association Chapter (NJ APDA) will host the **Have a Heart For Parkinson's Dinner Dance at Pierre's Restaurant in Monmouth Junction, New Jersey**. All proceeds will benefit the NJ APDA Chapter. We hope you will join us for an evening of dinner, dancing and laughter. Please see page for 11 for registration form and other details.

We are seeking auction items for the Have A Heart Dinner Dance. Auction items ideas include gift baskets of a value of \$50.00 or more, Broadway show tickets, sporting event tickets, signed sport memorabilia, etc. If anyone is interested in donating an auction item, please contact me by January 18. Thank you in advance for your consideration.

The Parkinson's Action Network's 14th Annual Research and Public Policy Forum will be held February 2-4, 2008 in Washington D.C. I have attended this event in prior years and have found it to be a worthwhile and fulfilling forum. Please refer to page 3 for details.

On Saturday, March 29, 2008, we will present our Annual Spring Living Well with Parkinson's Conference at The Pines Manor, Edison, NJ. Please save the date! Brochures with further details will be sent to you in February. We have a wonderful slate of speakers planned including Dr. Michele Tagliati, movement disorder specialist, Davis Phinney, Olympic cyclist and person with Parkinson's, and Dr. Dan Weintraub, a psychiatrist. Please join us for this event.

Look for more details about the Unity Walk and the bus (es) to the April Unity Walk in the next newsletter. You may also contact the Unity Walk in later December for the official walk date (**1-866-789-9255** or **www.unitywalk.org**).

Wishing you a very happy and safe holiday season! I hope to see you soon in the new year.

*Warm regards,
Elizabeth Schaaf*



*Treadmill Walking with Body
Weight Support*

Continued from page 1

Mitchell, Williams et. al. published two methods of training with the harness and treadmill. Their "Gait Training" employed walking at a faster than normal speed while supported on a treadmill walking forwards, backwards and to both sides. "Step Training" involved suddenly turning the treadmill on and off while standing in the harness facing in all four directions. Both of these methods demonstrated decreased falls versus a control group in the 8 weeks after training as well as an increase in cadence and an increase in stride length resulting in increased walking speed.

Since these initial articles were published, several more have followed with all pointing towards improvement in walking speeds or decreases in incidences of falling or improvement in balance scores. None of the articles I have read mentioned a change in assistive devices used by their participants after the study but one must wonder if indeed some participants were able to safely move to using a less intrusive assistive device.

Although research backs the idea of PBWTT it has been slow to spread into actual Physical Therapy practice. The equipment is expensive and some patients I have worked with had difficulty tolerating the harness used. Nevertheless, PBWTT can be a powerful tool to help people with Parkinson's get moving again. When coupled with exercises like tai chi, yoga, water aerobics or traditional

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*Ask the Neurologist
Column*

Would you like to propose a general Parkinson's related question to be answered by a movement disorder specialist? Your question and the answer may appear in the next newsletter column, "Ask the Neurologist".

Please send your general PD questions via email to Elizabeth.schaaf@rwjuh.edu or by mail to 120 Albany St, Ste 360 , New Brunswick, NJ 08901

**Deadline for submissions is
January 7, 2008.**





President's Notes
Benton Yip
NJ Chapter, American
Parkinson Disease
Association (NJ APDA)

Dear Readers,

It was disappointing that the stem cell ballot referendum was defeated in the last election, in a progressive state like New Jersey and as one of the top five states in spending in Research and Development in the U.S. Governor Jon Corzine underestimated the tremendous last minute push by opponents. Nevertheless, we should not rely only on stem cell research to find a cure for Parkinson's. Overall, more money should be raised for scientists for all avenues of scientific research in movement disorders. What is important is the need for funding for training neurologists specializing in movement disorders. Talking to several individuals with PD, my impression is that there are not enough trained movement-disorder specialists in our state. And because New Jersey is an expensive state for anyone migrating here to start a career and especially for young neurologists attempting to establish a practice after leaving medical school, some subsidies can be made available that would encourage doctors to stay in New Jersey and maintain their practice.

There is an excellent Movement Disorder Center at UMDNJ-Robert Wood Johnson Medical School, but as the number of newly diagnosed patients grow, as the population age, the time spent evaluating each patient could be reduced. The supply of movement disorder specialists is not evenly distributed in communities across NJ and raises questions about patient treatment and the appropriate follow-up medical care. We need to focus on getting our government to pay attention to elderly care, PD research, and overall funding in health care. Let's start thinking about strategies to encourage young doctors to focus on Parkinson's and movement disorder diseases. We may have lost the battle for stem cell funding but the war against Parkinson's is a fight we should continue. We need to be proactive by contacting our legislators regarding important health care issues affecting us and our families.

Wishing all a Safe and Merry Holiday and a Healthy and Happy New Year!

Sincerely,

Ben Yip, President, NJ APDA Chapter

Continued from page 2

physical therapy, the result can be a well rounded exercise can be a well rounded exercise program.

But if you prefer to walk alone in your own neighborhood, the important thing is to get moving and keep moving! ##



Congratulations ! 2007
Recipients of the
Excellence in Service
Awards:

NJ Moose Lodge Association

Annie Konopka

Bill Lear

All NJ Support Group Leaders



Join PAN for the
14th Annual
Scientific and Advocacy
Forum

February 2-4, 2008
Washington, DC

Scholarships are available,
but limited.
You must apply by January 2, 2008.

Phone-1-800-850-4726 or
202-842-4101
<http://www.parkinsonaction.org>

Deep Brain Stimulation and Parkinson's Disease

Hooman Azmi, MD

Movement Disorder Neurosurgeon, Hackensack University Medical Center/Valley Hospital

In the past few years, there has been much media attention given to surgery for movement disorders and in particular Parkinson's Disease. There are still however some misconceptions about the procedure and what it can do. It is important for any patient with Parkinson's disease considering surgery, their caregivers and their medical practitioners to have a good understanding of what the surgery entails, what are its risks, and what benefits it can provide. The following is a brief summary describing Deep Brain Stimulation surgery (DBS) for Parkinson's Disease. It is written in a question/ answer format for ease of reference. Many of the questions are actual questions that patients have asked me when being evaluated for candidacy for surgery. I hope that the readers will find this informative.

What is DBS?

Deep Brain Stimulation (DBS) is a surgical treatment for Parkinson's Disease, essential tremor and dystonia. It has been FDA approved in the US since 1997 and there have been over 35,000 implants performed worldwide for the treatment of movement disorders. DBS can be thought of as a brain pacemaker. The surgery entails placing a small wire in the area of the brain affected by Parkinson's disease. The wire is then passed under the skin down to the chest under the collar bone where the pacemaker is implanted. This brain pacemaker system, continuously delivers an electrical stimulus to the affected region of the brain. The electrical pulse is small and is not felt by the patient, however it is able to affect the activity of the brain to improve the symptoms of Parkinson's disease.

What are the benefits of surgery?

For someone considering surgery for Parkinson's Disease, it is very important to understand how DBS affects the different symptoms of Parkinson's Disease. DBS is not a cure for Parkinson's disease. The stimulation can help treat some but not all of the symptoms of the disorder. As a good rule of thumb, DBS works for symptoms that respond to levodopa. DBS is a very good treatment for tremor associated with Parkinson's Disease, for the rigidity or stiffness, for bradykinesia or slowness, and for dyskinesias which are the uncontrollable movements that are side effects of long term levodopa use. It also is great for minimizing the ON/OFF fluctuations that occur when someone has been

Taking medication for a long time. ON time is when a person has relatively good mobility and OFF time is when the mobility is lost as the medication effect wears off. Stimulation can smooth out the day and make more of the day as ON time for the patient. DBS does not help problems with speech, problems with balance or problems with cognition such as forgetfulness, decreased decision making abilities and difficulty with language and in fact it may worsen these if they are pre-existing.

When is someone considered a candidate for surgery?

Most patients with Parkinson's Disease respond well to medication and get relief of their symptoms. Patients are considered for surgery when the symptoms become difficult to manage with medication alone. When someone is taking a lot of levodopa or its equivalent on a daily basis, or have a medication frequency which is difficult to manage, or are having adverse side effects to the medications, they are considered good candidates for surgery. In addition, surgery is a good option when patients develop the uncontrollable movements called dyskinesias or are having multiple ON/OFF fluctuations during the day.

Why is surgery needed on both sides of the brain?

In general, one side of the brain controls the opposite side of the body. So DBS on one side of the brain will affect Parkinson's symptoms on the other side of the body. Patients with symptoms on both sides of their body will get their best relief with surgery on both sides of the brain. DBS leads can be placed on both sides during the same operation. The decision to go ahead with one side versus two, is usually made before the surgery and it depends on the patients symptoms, health and age. Some patients have symptoms that are mostly on one side of the body and these patients may get very good relief with one sided surgery. In patients who may be more elderly or have health issues and need stimulation on both sides, the two sided surgery can be staged with one side done in one operation and the other done several weeks later.

What are the risks of surgery?

Any surgery has risks and this is no different with DBS. The responsibility of the treating team is to weigh all the risks of surgery and the benefits that DBS may provide for the patient and decide if it is reasonable to offer surgery to that particular patient.

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Hallucinations in Parkinson's Disease

Jacob Sage, MD, Professor of Neurology, UMDNJ-RWMS

Parkinson's disease (PD) traditionally has been classified as a motor system disease. The diagnosis has relied on three major motor symptoms and signs, resting tremor, rigidity and bradykinesia (slowness). Additional signs of motor system involvement include diminished fine motor coordination, abnormalities of gait including dragging of a leg, shuffling and freezing, disturbances of posture and postural stability, problems with balance, flattening of facial expression and softness of speech. This emphasis on the motor system abnormalities was reinforced in the late 1960s with the successful advent of levodopa therapy. Levodopa which is converted in the brain to the neurotransmitter dopamine ameliorated many but not all the motor signs and symptoms of PD. In the very first few months after treatment with levodopa began in the 1960s it was even thought that it might be a cure for PD. Quickly however motor fluctuations and dyskinesias appeared as significant side effects of treatment and it was realized that a cure would have to be found elsewhere. But the idea that PD was simply and solely a motor system disease persisted for decades.

For the past decade it has become increasingly evident that PD should be regarded as a more generalized disorder rather than a strictly motor disease. In addition to the major signs and symptoms referable to the motor system, autonomic, sensory and cognitive issues play major roles in discomfort and disability in PD patients. In fact some of the most common problems occur in the cognitive/psychological arena with depression and hallucinations being major sources of disability. In this article, we will focus on the issue of hallucinations in patients with PD.

An hallucination is defined as a perception of something in the environment that is in fact not there. Hallucinations in PD patients come as three major types: olfactory, auditory and visual. Visual hallucinations are by far the most common. They range from mild to severe. Mild hallucinations often start with the patient reporting a sensation that there is a shadow off to one side of the visual field. These sensation are intermittent. Some patients report that they look at an object in the distance and think they see a person or animal but the object turns out to be a fire hydrant or telephone pole, etc. These are more correctly termed illusions or

delusions but for our purposes can be classified with the hallucinations. As hallucinations get more serious patients report seeing people, often children, animals or insects. These hallucinations are not precipitated by looking at an object but seem to occur for no reason at all. Severe hallucinations are those which are accompanied by paranoia or are frightening in some other way. The patient is afraid that the people in the hallucination are going to harm him in some way. Patients sometimes react violently to such hallucination or may call the police or in some other way act irrationally.

The processes of advancing disease in PD patients make them prone to develop hallucinations. In fact certain forms of parkinsonism with more early diffuse involvement of the Lewy body pathology in the brain may get hallucinations early in the course of the disease. In most patients hallucinations are prone to be a factor late in the disease. The important thing to remember is that the medications used to treat the motor symptoms and signs of PD tend to make hallucinations worse.

The first treatment to try and decrease hallucinations is medication reduction where this is possible. Reducing and eliminating medications should start with the drugs most likely to worsen hallucinations. Depending on circumstances most patients reduce the anticholinergic medications (Artane, Cogentin) and the direct acting dopamine agonists (Requip, Mirapex, Neuropro) first. After that the catechol-o-methyl transferase inhibitors (Comtan) can be decreased and discontinued. Finally levodopa reduction may be necessary. It is often hard to decrease levodopa because it is so essential for controlling the motor symptoms of PD. In that case drugs like quetiapine can be added. This agent acts directly to reduce the tendency to have hallucinations.

It is important to recognize hallucinations and to report them to the doctor. They are nothing of which a patient need be ashamed. If left unchecked, hallucinations can lead to irrational and antisocial behavior that can be very difficult on patients and families. ##



SAVE THE DATE!

**Painting with Parkinson's
For Peace of Mind
(for people with PD and
their families)**

**Fridays, May 9, 23 and 30
1:00 PM to 3:00 PM
RWJUH, New Brunswick, NJ**

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Risks of anesthesia include an allergic reaction to medication, heart attack, airway problems and death. These risks are extremely small (less than 1%) and are minimized by a preoperative medical evaluation.

There is a risk of hemorrhage during surgery however this risk is quite small (about 2%), even if it occurs, it is usually something that does not affect the patient and is only seen on a CT scan of the brain. Very rarely hemorrhage may need to be surgically evacuated, or cause stroke like symptoms.

Risk of infection. Just as in any other implant procedures such as heart pacemakers or even knee replacements, there is a risk that an infection will occur after the surgery. We are always extremely diligent and adhere to a strict sterile technique to minimize infections. Some centers prefer to place patients on oral antibiotics for a few days after the surgery. Despite this infections do happen in about 4-5% of patients, and it is important to be aware of this risk as well.

There is also a risk of developing neurological complications such as weakness, paralysis or difficulty with speech. These risks are very small and are minimized by the use of computer guidance during the procedure.

In addition there are reversible side effects as the result of the stimulation such as tingling, tightening of muscles and double vision which can be reversed by changing the stimulation settings.

How is the surgery performed?

Surgery is generally done in two stages. The first stage is the placement of the DBS lead or wire. To obtain the best result from surgery, the exact location of the DBS lead is very important. To this end most centers that do DBS surgery use state of the art computer guidance and brain mapping techniques to identify the perfect location for the DBS lead. To help find that exact location rigid frame or a "halo" is placed on the patients head during the surgery. The lead is placed through a small incision in the scalp and a small opening in the skull. The patients cooperation during the surgery is also very important in finding the perfect location for the DBS and therefore patients remain awake during the parts of the surgery where we would need their participation. For the remainder of the surgery, patients are under some anesthesia. Patients should not have any discomfort during any part of the procedure and part of the goal of the surgical team is to make sure that is the case for all patients. After the surgery, patients usually stay

in the hospital about 2 to 4 days. They are then discharged to home.

The second stage of the DBS procedure is the implantation of the battery and it is done usually about one to two weeks after the First stage. It is an outpatient surgery and patients are placed under complete anesthesia. Once the surgery is done, patients are discharged home on the same day.

When will the DBS start working?

About 4 weeks after surgery, the stimulator is turned on by the team. This is done in the office, with remote control communication with the brain pacemaker. About once a month, the stimulator is adjusted and within 4-6 months the settings will be stabilized. After this initial programming session, the required visits are for checking the system and are about once or twice a year.

Is there maintenance required for the system?

Once the settings are stabilized, the system should be checked about once or twice a year to ensure that it is working properly. The battery will need to be changed in about every 4-5 years, and this is also done as a same day procedure, and only requires a battery change and not any replacement of the brain lead.

What if I have undergone DBS and a cure is discovered?

DBS does not destroy or damage any part of the brain. It can be removed to allow for other procedures if gene therapy or transplant therapy prove to be better treatments or a cure for Parkinson's disease.

Do I have to limit my activities after DBS?

The purpose of surgery is to restore a patients quality of life, and not to limit them from activities they enjoy. Patients can be active and engage in sports after DBS .

How can I get more information about surgery?

There are some excellent sources of information for surgery for Parkinson's Disease. The American Parkinson's Disease Association, The Parkinson's Alliance, and the National Parkinson's foundation have great resources for people with Parkinson's in general and also for surgery for Parkinson's disease. Also reach out to a support group in your area, they could be a valuable source of information. # #

Especially For You Caregiver Support Group!*Robert Wood Johnson**University Hospital, New Brunswick***Meets the First Tuesday of each month****(except in January 2008)****7:00 PM****Please email Gail Nemeth at Esp4YouSupport@aol.com****Or call (732) 418-8110 for more details.**



Scenes from Fall Conference November 10, 2007 The Mansion-Voorhees, NJ



Conference attendees at the Fall Symposium at The Mansion.



Dr. Matthew Menza, Department Chair of Psychiatry at UMDNJ-Robert Wood Johnson Medical School presenting on Non-Motor Symptoms of PD.



Stacie Mishler, Events Director for the Parkinson's Unity Walk and speaker and author of *The Silence of Bunnies*, Dan Stark pose for a moment during the conference.



Dr. Daniel Kremens, Assistant Professor of Neurology with Jefferson Medical College of Thomas Jefferson University presenting to the attendees on the Medical Management of Parkinson's.

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 most of the day*
- ◆ *Fell empty most of the day*
- ◆ *Difficulty falling asleep*
- ◆ *Difficulty 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**

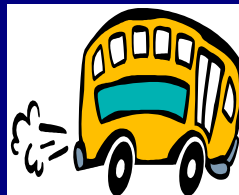
A Study of Insomnia in Patients with PD

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**



Buses To Parkinson Unity Walk

The New Jersey Chapter of the American Parkinson Disease Association (NJ APDA) will take at least one bus to the Unity Walk for Parkinson's disease in Central Park, in April 2008 (date to be announced).

***Look for details
in the February 2008 issue of the
Parkinson Bulletin.***

Using the Alexander Technique as an alternative therapy for Parkinson Patient Self-care

Diane Young

Since April of 2006, the Alexander Technique has been officially on the Parkinson's patient's radar. The American Academy of Neurology cited the Alexander Technique as a viable alternative therapy for patients wishing to address issues of balance, speech control, control of tremor, and anxiety reduction. This came from a study conducted in London, "Randomized controlled trial of the Alexander Technique for idiopathic Parkinson's Disease", C.Stallibrass, Sissons, and Chalmers; *Clinical Rehabilitation*, Vol. 16, No. 7, 695-708 (2002). The Alexander Technique is a hands-on educational modality that addresses issues of muscular tension long held within the body. It works by accessing the person's thinking process to change inefficient habits which limit free movement. A trained Alexander Technique teacher will assist the client both with hands-on guidance and with verbal instructions, to encourage changes in the way the client moves and carries out an activity, to release habits and patterns of tension which are not useful. The progression of Parkinson's disease frustrates many a person, in time diminishing the effectiveness of carrying out even the most ordinary of daily activities. Actions such as walking, sitting, putting on a shoe once taken for granted eventually require a great deal of effort and concentration. Washing and putting on clothing can suddenly take hours. The Alexander teacher will regard these so-called simple activities with utmost care, and approach each movement choice systematically, offering new solutions in carrying them out.

For example, if the client presents with the Parkinson's gait, including the tendency to lean forward and use small, quick steps as if hurrying, the Alexander teacher will bring hands to the head/neck area, and encourage a lengthening upward of the spine before the action is to begin. As the client is able to respond to the upward flow and not attempt to move forward, there is a possibility for him to stay in a balanced poise before the action is initiated. This small change can then effectively change the whole movement pattern including less stiffening, and more steadiness in the resultant walking. The freezing tendency can also be addressed by offering the client something to think while the freezing is taking place. In Alexander terms this is called

"directing", which is an internal process of thinking in particular ways about the bony structure and the intention for movement.

The objective is to bring the client onto a neutral balance where the head and spine are not being pulled forward of the axis. The overworking muscles can be gently coaxed into a more elongated and flexible balance, allowing the musculature of the back to neither over-stretch nor over-tighten. Interestingly, this is not done by the usual command to "stand up straight". Instead there is a delicate re-balancing of the skeletal parts which allows for the natural reflex mechanism to operate automatically and for the normal balance of the musculature to work efficiently. As the head comes onto the top of the spine instead of being pulled forward to create the pronounced drop in posture, the musculature that supports the front of the torso is allowed to release into a longer resting length. This change is effected by learning to listen to body position, or the kinesthetic sense, and to organize movement in this new way.

Balance is restored by encouraging the client to get the head over the spine. In this way, the postural reflexes get activated by finding a particular balance for the head on the top of the spine, which automatically elicits a positive anti-gravity response. Nature takes care of the details; the body finds balance by not interfering with the inherent ability to be upright in an easeful way. The right thing works because the downward pulls on the body are eliminated. This is why it is so essential to get the client re-balanced over his feet. The belief that one cannot go forward perpetuates some of the downward pull that then activates to exaggerate the slump, which of course perpetuates the slump!

Understanding that the very nature of the disease creates the condition, with conscious thought and a formula for organizing the various skeletal parts in an efficient way, the client has a means to challenge the progressive tightening within his body, and to at least counter the inevitable movement rigidity. This is accomplished by applying a set of conscious commands to his movement choices. This same is true for speech. The client is given a protocol for specific movement choices which can go a long

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Upcoming Educational Events and Support Group Meetings January-April 2008

RWJUH Parkinson Support Groups

Afternoon Meetings

Meets the third Thursday of the month
(unless otherwise noted).

**Time: 12:30 PM Place: Auditorium
Robert Wood Johnson University Hospital,
New Brunswick, NJ**

**Meeting location is subject to change; day of meeting
please call (732) 745-7520 to confirm location.**

Afternoon meeting dates are:

Thursday, January 17, 2008

Topic: Newest Development in Physical
Therapy

Speaker: David King, PT

Thursday, February 21, 2008

Topic: The Alexander Technique and PD
Speaker: Diane Young

Thursday, March 20, 2008

Topic: Ask the Nurse Practitioner about PD
and Clinical Trials

Speaker: Debbie Caputo, NP,
UMDNJ-RWJMS

Evening Meetings

Meets the third Wednesday of the month
(unless otherwise noted).

**Time: 7:00 PM Place: Auditorium
Robert Wood Johnson University Hospital,
New Brunswick, NJ**

**Meeting location is subject to change; day of meeting
please call (732) 745-7520 to confirm location.**

Evening meeting dates are:

Wednesday, January 16, 2008

Topic: Ask the Neurologist

Speaker: Jacob Sage, MD, UMDNJ-RWMS

Wednesday, February 20, 2008

Topic: Newest Development in Physical
Therapy and PD

Speaker: David King, PT

Wednesday, March 19, 2008

Topic: Ask the Nurse Practitioner about PD
and Clinical Trials

Speaker: Debbie Caputo, NP
UMDNJ-RWJMS



Have A Heart For Parkinson's Dinner Dance

Annie Konopka will host the 2nd
Annual Dinner Dance to benefit the NJ
APDA Chapter. Saturday, February 9, 2008 at Pi-
erre's in Monmouth Junction, NJ. Seats are limited.
Please see page 11 for details.



Excellence in Service Award

We are accepting nominations for the 5th
Annual Excellence in Service Award. You
may nominate an individual who is active
in the Parkinson Community. Examples
include a support group facilitator, volunteer, care-
giver, or person with Parkinson's who is an inspira-
tion to others and Parkinson advocates. *Please no
political officials. Submissions are due by Friday,
February 1, 2008.*

Annual People with Parkinson's and Family Conference

Annual educational symposium on Saturday, March
29, 2008, at the Pines Manor, Edison, NJ; 9:30 AM
to 3:15 PM. Scheduled speakers include: Olympic
Cyclist and Person With PD Davis Phinney; Neurolo-
gist-Movement Disorder Specialist Michele Tagliati,
MD; and psychiatrist Daniel Weintraub, MD. Details
in next newsletter.



Parkinson Unity Walk-

Saturday, April 2008 (date to be an-
nounced) NYC's Central Park. Please call
toll free: 1-866-PUW-WALK (1-866-789-
9255) fax: (609) 688-0875. Website: [http://
www.unitywalk.org](http://www.unitywalk.org).



PHONE SUPPORT GROUP

This series conveniently meets by telephone!
"Meeting" Monday evenings at 7:30 PM on
April 28, May 5, 12 and 19, 2008. This is an
opportunity to join with other people to
share and discuss issues related to Parkinson's. The
group is open to people with PD, family, friends and
caregivers. Elizabeth Schaaf will facilitate the series.
Total cost: \$25.00. Guest speakers: TBA. Scholar-
ships are available. DOROT places the calls to your
home and pays for them as well. For more info, or to
register, call **DOROT at (877) 819-9147.**

SAVE THE DATE

Saturday, February 9, 2008

*Join us for a night of
Dinner, Dancing and Laughter*

Annie Konopka hosts the
2ND Annual

***Have a Heart for Parkinson's
Valentine's Dinner Dance***



Featuring Comedian Mike Morse

Mike has appeared on MTV, VH-1, Comedy Central and E! Entertainment.
He is a winner on ABC-TV's popular show, America's Funniest People

Silent Auction

Pierre's of South Brunswick, Monmouth Junction, NJ

7 p.m. to 11 p.m.

\$65 per person or Reserved Table (of 10)

Full table reservations close Jan 18. Individual ticket sales close Jan 31.

**Proceeds to benefit the NJ Chapter American Parkinson Disease Association
(501c3 org)**

Questions? (732) 821-5415

Registration for Have A Heart For Parkinson's Dinner Dance

Please mail to: Annie Konopka, 20 Palmer Road, Kendall Park, NJ 08824
Make checks payable to: Have A Heart For Parkinson's To Benefit NJ APDA

Name _____ Daytime Phone _____

Name(s) of other attendees _____

Address _____

Email _____

Number of tickets _____ Amt Enclosed _____



New Jersey Parkinson's Support Groups

ATLANTIC COUNTY

Absecon Presbyterian Church

208 New Jersey Avenue, Absecon, NJ 08201

Meetings: Monthly, 1st Thursday

No January, July or August meeting

Time: 2:00 - 4:00 p.m.

Contact: Karen Muldoon (609) 926-8440

BERGEN COUNTY

Parkinson's SG of Greater Ridgewood

Cedar Hill Christian Reform Church
422 Cedar Hill Avenue, Wycoff, NJ 07481

Meetings: Monthly, 1st & 3rd Thursday

No Speaker's - July, August or December meetings

Time: 1st Thursday-caregiver's meeting and separate persons with PD meeting -7:30 PM

Third Thursday-Guest Speaker-7:30 PM

Contact: Marion Arenas (201) 670-0083

Northern Valley Support Group

First Congregation Church
276 Haworth Ave, Haworth, NJ 07641

No July or August Meetings

Meetings: Monthly, 1st Saturday

Time: 1:00 p.m.

Contact: Ilse Heller (201) 265-4976

Myra Teplitzky 201-652-8628

Englewood Exercise Program & Support Group

Southeast Senior Center/Independent Living
228 Grand Avenue, Englewood, NJ 07631

Meetings: Every Friday

Time: 1:00-3:00 p.m.

Contact: Partica Marshall (201) 224-8816

Ilse Heller (201) 265-4976

BURLINGTON COUNTY

Virtua Memorial Hospital

62 Richmond Avenue, Mount Holly, NJ 08060

Meetings: Monthly, 3rd Wednesday

No December meeting

Time: 7:00PM- 8:30PM

Contact: Amy Gallagher (856) 322-3080

CAMDEN COUNTY

NO ACTIVE SUPPORT GROUPS

CAPE MAY COUNTY

Victoria Commons

610 Town Bank Road, North Cape May, NJ 08204

Meetings: Monthly, 2nd Tuesday

No July or August meetings

Time: 1:00 p.m.

Contact: Rita Tumaszk (609) 886-2455

CUMBERLAND COUNTY

NO ACTIVE SUPPORT GROUPS

ESSEX COUNTY

North Jersey Support Group

Mountainside Hospital (Private Dinning Room)
One Bay Avenue, Montclair, NJ 07042

Meetings: Monthly, 3rd Saturday

Time: 10 a.m.-12:00 p.m.

Contact: Betty (973) 376-3365

Ginny (973) 890-3113

GLOUCESTER COUNTY

Southern New Jersey Support Group

Woodbury Mews

122 Green Avenue, Woodbury, NJ 08096

Meetings: Monthly, 1st Wednesday

No July meeting

Time: 7:00 PM

Contact: Diane Gruszewski (609) 254-3096

HUDSON COUNTY

NO ACTIVE SUPPORT GROUPS

HUNTERDON COUNTY

NO ACTIVE SUPPORT GROUPS

MERCER COUNTY

Central Delaware Valley Support Group

Lawrenceville Presbyterian Church
Route 206, Lawrenceville, NJ 08648

Meetings: Monthly, 3rd Wednesday

No Jan, Feb, July, Aug meetings

Time: 1:00 p.m.

Contact: John Wicoff (609) 737-3364

MIDDLESEX COUNTY

Later On-Set Patient & Family Support Group

RWJ University Hospital, Auditorium
New Brunswick, NJ 08901

Meetings: Monthly, 3rd Thursday (with exceptions due to some holidays)

Time: 12:30 - 2:30 p.m.

Contact: Elizabeth Schaaf (732)745-7520



New Jersey Parkinson's Support Groups

MIDDLESEX COUNTY

Young Onset Patient & Family Support Group

RWJ University Hospital, Auditorium
New Brunswick, NJ 08901

Meetings: Monthly, 3rd Wednesday

Time: 7:00 p.m.-9:00 p.m.

Contact: Elizabeth Schaaf (732)745-7520

Monroe Township Senior Center

1 Municipal Plaza, Monroe Township, NJ 08818

Meetings: Monthly, 1st Wednesday

Time: 1:00-2:30 p.m.

Contact: Janice Dibling (732) 321-7063

MONMOUTH COUNTY

Red Bank Area Self-Help Group

United Methodist Church **No summer meetings**

247 Broad Street, Red Bank, NJ 07701

Meetings: Monthly, 2nd Tuesday

Time: 2:00 p.m. please call first

Contact: Rosalind Seawright (732) 751.3451

Senior's First Parkinson's Support Group

Manalapan Senior Center

211 Freehold Road, Manalapan, NJ 07726

Meetings: Monthly, 3rd Tuesday

Time: 11:15 a.m.

Contact: Janet Burns (732) 780-3013

MORRIS COUNTY

Care One at Madison

151 Madison Ave, Morristown, NJ

Meetings: Monthly, 1st Monday

Time: 11:30 a.m.

Contact: Carol Carlson (973) 714-7652

Parkinson Exercise Program at Madison YMCA

111 Kings Road, Madison

Classes: Every Wednesday, 1:30 p.m.-2:30 p.m.

Contact: Susan (973) 822-9622

Care One at Parsippany

200 Mazdabrook Road, Parsippany, NJ 07054

Meetings: Monthly, 3rd Monday

Time: 1:45 p.m.

Contact: Carol Carlson (973) 714-7652

PASSAIC COUNTY

NO ACTIVE SUPPORT GROUPS

OCEAN COUNTY

Parkinson's Life Enrichment Program

Ambulatory Care Center at Ocean Medical Center
425 Jack Martin Blvd. Brick, NJ

Exercise Classes: Tuesdays, 6-week session

Time: 11:00 a.m.-12:00 p.m., \$79

Contact: (732) 836-4007

Susan Delmar or Gabriel White

SALEM COUNTY

NO ACTIVE SUPPORT GROUPS

SOMERSET COUNTY

Fellowship Village (Grill Room)

8000 Fellowship Road, Basking Ridge, NJ 07920

Meetings: Monthly, 3rd Tuesdays

Time: 1:30-3:00 p.m.

Contact: Maria Santo (908) 580-3836

SUSSEX COUNTY

Eleanor Chaplin Memorial Support Group

Senior Center-Lower Level,

La Banc Lane, Franklin, NJ 07416

Meetings: Monthly, 3rd Friday

Time: 1:00-3:00 p.m.

Contact: Anita Navara (973) 948-3329

UNION COUNTY

RWJ University Hospital, Rahway

865 Stone Street, Rahway, NJ 07065

Meetings: Monthly, 2nd Wednesday

Time: 1:00 p.m.

Contact: Debbie Hargiss-(908) 272-2362

The Presbyterian Church in Westfield

140 Mountain Avenue, Westfield, NJ 07090

Meetings: Monthly, 2nd Monday

Time: 1:30-3:30 p.m. **No July or August meetings**

Contact: Barbara Ringk (908) 322-9214

WARREN COUNTY

NO ACTIVE SUPPORT GROUPS



SAVE THE DATE!

Are You A Support Group Leader or do you wish to start a new Parkinson's Support Group?

Don't Miss:

Parkinson's Support Group Networking and Workshop

Friday, May 2, 2008 10:00 AM-2:30 PM

East Brunswick Public Library

East Brunswick, NJ

Using the Alexander Technique Continued from page 9

way to minimizing the challenging condition of slurred speech. The teacher will help the client practice "active inhibition" to minimize muscular tension patterns within the throat, tongue, and facial musculature, and to practice speaking with less effort, giving the tongue time to relax more while speaking. Some of the actions of the musculature are purely mechanistic, and require a conscious approach to effect change in the muscles that so quickly become encumbered during the attempt to speak. F.M. Alexander, the developer of the technique made this discovery more than 100 years ago, observing his own tension patterns while in the act of speaking. There is a tendency to overwork all of the musculature of the speaking mechanism as well as distorting the skeletal alignments while speaking. This is true for all of us, but particularly useful to explore if speech has become impacted because of the Parkinson's. The Parkinson's patient is an ideal candidate for such re-education, with its emphasis on muscular re-balancing, skeletal co-ordination and postural poise.

The Alexander teacher would treat the Parkinson's patient the same as any student coming for lessons. He would examine the habitual use-related tendencies that the client presents, and systematically re-educate the patterns of behavior and use which limit free movement. To this end, it is highly recommended to study the Alexander technique early in the treatment process so that the patient can master some of the new skills. As the progression of the disease necessitates a more aggressive movement re-education, one can recognize the neurological degeneration as it comes, yet can meet the changes with the enhanced understanding and skill offered through lessons. The awareness and kinesthetic understanding learned through the study of the Alexander principles will inform the client in such a way that one can literally have different movement choices available to them. Teaching oneself not to move in a reactive way to a stimulus, but instead to first release into expansion and to find head balance, is the right choice for movement and this skill is learned through taking Alexander lessons. Everyone has tension habits that lead to restricted movement and postural difficulties; when someone is also

diagnosed with Parkinson's disease, he can use this method to address some of the balance and movement control issues that develop, and hopefully can stay just ahead of the curve where one's quality of life, independence, and well-being can be impacted in a positive way. In an Alexander lesson it is the job of the teacher to challenge the client's beliefs, assumptions, and movement habits, even under conditions created neurologically by the disease. With practice the client is able to secure much more control in their movements, leading to more ease, grace, and poise in the carrying out of his activities. For example, I once was instructing a client to get up from the chair without tightening his legs and pulling his torso down. I put hands at his head/neck and encouraged him to think of the head leading out and the spine having length instead of curving forward into a slump. He believed that the only way he could get up from the chair was by tightening down in this way and rocking himself forward. I knew he could get up without doing this compressive action. I was very persistent in not allowing the front to shorten or for the legs to tighten and pull in, and eventually he tried to do it my way instead. I was amazed at how effortlessly he lifted right out of the chair. This was a contest of the mind, not the body. In re-directing his body to go up and not down he had challenged his belief about the habitual movement choice. This was not a necessity demanded by the neurological condition but a willingness to do his standing in a new and unfamiliar way. For this one client there was a window of opportunity to develop a new way of getting out of the chair by re-directing his thinking and changing his belief about what the movement required. For him it led to renewed freedom of movement, and also hope for being more in control of his body. A new experience was attained in the moment, which with consistent practice would have the ability to off-set the challenging changes experienced by the progression of the disease.

The Alexander process can and does offer assistance and support for the Parkinson's patient. Please go to our national website for more information and to find an Alexander teacher in your area. www.amsat.ws, (800) 473-0620, or go to www.acatnyc.org, (212) 633-2229. For other information, you can also check out my website at www.bodymindbalance.net.



Parkinson Disease Clinical Trials

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

Go to www.pdtrials.org

NJ Chapter American Parkinson Disease Association Annual Membership Form

***Individual Membership Fee \$10.00/year
Family Fee: \$ 15.00/year***

Name _____

Phone _____

Address _____

Email _____

I am interested in:

NJ APDA Board Activities

Fundraising

Advocacy Issues

Research and Education

Assisting with Health Fairs/Events

Desired location to assist with events

Northern NJ

Central NJ

Southern NJ

Other areas

Please send to:

Benton Yip

APDA New Jersey Chapter

PO Box

Edison, New Jersey 08818

**Please make check payable to:
NJ Chapter APDA**

Moving-Breathing Study

Dr. Diana Glendinning a neuroscientist and professor at Seton Hall University, Department of Physical Therapy is conducting a research study to look at how breathing and movement are coordinated in people with Parkinson's disease. This can help with the development of new physical therapy treatments for Parkinson's disease. She needs subjects for a small research project to be conducted by physical therapy students.

For this study, you would come to Seton Hall University for 1.5-2 hours. Sensors will be placed on your hip, shoulder, head and under your nose, to take measurements of your body as you move, together with your breathing. Also we will ask you to stand up and reach forward, stand from sitting, or walk. You will do these motion exercises several times.

Please consider volunteering if you have mild Parkinson's disease or if you don't have Parkinson's disease but can be a "control" subject. You will get the results of your measurements right away!

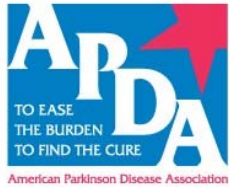
For questions or to volunteer, contact Dr. Glendinning at e-mail Glendidi@shu.edu or at 973-275-2918. You will be asked several questions to determine your eligibility.



Donations Needed for Have a Heart for Parkinson's Dinner Dance Raffle

***Seeking gift baskets or other prizes
(tickets to restaurants, Broadway show tickets,
sporting event tickets, sports memorabilia, etc.
at a value of \$50.00 or more)***

**Please call Elizabeth at (732) 745-7520 if you
are able to donate an item.
Items are needed by January 18, 2008.**



*New Jersey Parkinson Disease Association
Information & Referral Center*

Jacob Sage, MD
Professor of Neurology
Chief, Movement Disorder Clinic
UMDNJ/RWJMS

Medical Director, NJ/APDA
Parkinson Disease Information &
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Edison, New Jersey 08818
Yipcaptital@yahoo.com

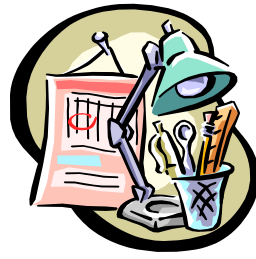
American Parkinson Disease Association National Office
Parkinson Plaza
135 Parkinson Avenue
Staten Island, NY 10305-1425
1-800-223-2732

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



ROBERT WOOD JOHNSON

UNIVERSITY HOSPITAL



SAVE THE DATES

Have a Heart For Parkinson's Dinner Dance

Saturday, February 9, 2008

7:00 PM to 11:00 PM

Purchase your tickets today!

(More details on page 11)

Annual People With Parkinson's and Family Educational Conference

Saturday, March 29, 2008

9:30 AM to 3:00 PM

The Pines Manor, Edison, NJ

(More details February 2008 Newsletter)

Parkinson Unity Walk

April 2008 (exact date-TBA)

New York's Central Park

(More details February 2008 Newsletter)



Parkinson Bulletin

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