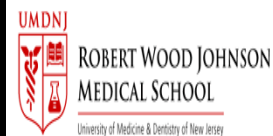




The Parkinson's Bulletin

December 2009/February 2010



Winter 2009-2010



The NJ/APDA Parkinson Disease
 Information and Referral Center
 120 Albany Street, Suite 360, New Brunswick, NJ 08901
 (732) 745-7520-office (732) 745-3114-fax
 www.njapda.org

Deep Brain Stimulation as an Adjunctive Treatment for Parkinson's Disease, Eric Hargreaves and Dr. Shabbar Danish, UMDNJ-Robert Wood Johnson Medical School

In Parkinson's Disease (PD), a gradual loss of dopaminergic neurons in the substantia nigra of the brain unbalances the downstream output of the basal ganglia motor system. This imbalance leads to tremors, akinesias, and bradykinesias. Deep brain stimulation (DBS) attempts to re-balance the basal ganglia output by passing continuous trains of fast, small, electrical pulses through the tips of electrodes surgically implanted in neural targets that are the final stages of this circuitry. DBS is an adjunctive therapy in that it does not replace PD medications, although doses are frequently lowered by half, reducing medication induced dyskinesias.

Does DBS work?

Many well controlled clinical studies report a 30-70% improvement in any of the tremor, akinesia and bradykinesia symptoms as rated by Part III of the Universal Parkinson's Disease Rating Scale (UPDRS), and a 40-49% improvement in the Activities of Daily living Part II of the UPDRS. These improvements are equivalent to the best medical response to levodopa (sinemet), but without the dyskinesias and the on/off motor fluctuations. Further, DBS has little effect on the more axial symptoms of PD related to freezing, balance and falling, or the late stage mental status decline. Finally, DBS, only

treats the symptoms of PD, and does not have any neuroprotective effect, meaning that DBS does not stop or slow down the progression of PD.

Does DBS work for everyone with PD?

Not everyone with PD or Parkinson-like symptoms will benefit from DBS. Thus, a careful screening process is undertaken to identify candidates, who will maximally benefit from DBS. The leading predictor of success is a good response to levodopa, even if the doses now required to control the symptoms also produce dyskinesias or on/off motor fluctuations. There are also caveats to DBS candidacy, such that already present cognitive difficulties or psychiatric disorders are contraindications to DBS, since the treatment may make these issues worse. However, every candidate is evaluated on a case by case basis, and if the potential outcome benefits can outweigh the contraindications, then the candidate may be accepted.

Are there risks to DBS?

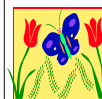
DBS has become a standard FDA approved treatment for a number of movement disorders throughout the last decade and there are now over 60,000 people with DBS world wide. That said, DBS does involve brain surgery, and is therefore not without associated adverse events (AE), such as intracranial hemorrhages (ICH) and infections, but in most centers these incidents occur less than 3% of the time.

Continued on page 5

INSIDE THIS ISSUE:

Deep Brain Stimulation and PD	1
President's Notes and Chapter Year in Review	3
Thank you to Our 2009 Event Sponsors	4
If a Fall Happens	5
Bladder Problems and PD	7
Caregiving and Parkinson's Disease	9
Upcoming Events and Programs 2010	10
Strike out PD March 21 Bowlathon	12
NJAPDA Membership	13
Parkinson's Support Groups in NJ	14

Save the Date!
Annual Spring PD Conference
 Saturday,
April 10, 2010
The Imperia Somerset 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.

Before this year comes to a close, I want to share with you a preview of our 2010 events:

On **Sunday, March 21, 2010**, the NJ American Parkinson Disease Chapter invites you to participate in our *Strike Out Parkinson's* Bowl-a-thon Fundraiser. More details to follow. We will need your help cultivating teams for this fun event. The proceeds from this event will go to research and to support the New Jersey Information and Referral Center.

On **Saturday, April 10, 2010** we will present our **Annual Spring Living Well with Parkinson's Conference at the Imperia in Somerset, NJ**. Brochures with further details will be sent to you in February. We have a wonderful slate of speakers planned for you. Please join us for this event. Save the date and help us spread the word.

Look for more details about the 2010 Parkinson's Unity Walk and the bus to the walk in the next newsletter. You may also contact the Unity Walk in later December for the official walk date. Call **1-866-789-9255** or visit **www.unitywalk.org**.

I want to take this opportunity to thank the support group members and support group leaders who attended the Westfield Support Group meeting on September 14, 2009 to thank me. The cards, beautiful album and other generous gifts were greatly appreciated; it has been so wonderful working with all of you and I look forward to helping as much as possible in the upcoming year.

Wishing you a very happy and safe holiday season! I look forward to seeing you in 2010.

Warm regards,

Elizabeth Schaaf

NJ American Parkinson Disease
Association Information and
Referral Center
Elizabeth.schaaf@rwjuh.edu
Www.njapda.org



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. **Participation may take place over the phone for those who are unable to travel.**

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



President's Notes-Vicki Collier New Jersey Parkinson Disease Association

Reflecting on the highlights of NJ APDA's accomplishments as 2009 comes to a close, it is fitting to recognize and commend all members of the NJ PD Community who contributed to the success and the fun. Since the NJ Chapter is responsible for financing education and research for Parkinson's, our lifeline is the participation and generosity of members. Thanks to the success of the fundraisers early in the year, for the first time our Information and Referral Center was able to offer three regional conferences rather than the historical two. Proceeds from recent events highlighted below will help fund our 2010 education and research objectives, as will our Learning Express Shopping Days and Poinsettias for Parkinson's fundraisers. By volunteering your time and resources, we will raise the \$20,000 necessary to ensure similar program success in 2010. We need your help! I am grateful for the opportunity to serve you, and I wish you peace, good health, and happiness during this holiday season and beyond.



Putt for Parkinson's Miniature Golf Fundraiser, August 09, 2009

Ilana Horowitz contacted NJ APDA to initiate a fundraiser in her grandfather's honor. With tremendous support from the Branchburg NJ community, this event helped putt-putt the way to **over \$3,500** for NJ APDA educational programs.



*Ilana and her grandparents relax before golfing (L)
Joan and Kevin dazzle Bridgewater Commons! (R)*

Macy's Shop for a Cause PD Research Fundraiser, October 2009

When NJ APDA Vice President Cindy Yaros noticed an ad in her local paper inviting local charities to partner with Macy's in a national fundraising campaign, she knew it would be a perfect match for our Chapter and she was right! Board Members Kevin Hinkle and Joan deRuiter took it from there and helped deliver **\$2,500** for Parkinson's disease research. Special thanks also go to the Student Nurse Association at RVCC, the many individuals who purchased shopping passes at our October symposium in Teaneck, and those who responded to our email and newsletter appeals.

Kowall Family Reunion

Elizabeth Kowall and family generously donated \$251 in memory of Bill Wall, to the NJ APDA as part of their annual family reunion. What a great and thoughtful gift!



Shake, Rattle, and Roll 50's Dance Fundraiser, September 12, 2009

What do energy, imagination and a step back in time have in common? Clearly it's Allan Bleich! Undaunted by a diagnosis of Parkinson's disease, Allan decided to have a fundraiser dinner dance party with a 1950's theme, and what a party it was! With the help of family and friends, "Shake, Rattle, and Roll for Parkinson's disease" was a huge success. Leather jackets and poodle skirts abounded and dancing to 50's music was clearly in swing. Allan acknowledges that without the outpouring of support from family, friends, benefactors, and the APDA, the event could not have been the social and financial success that it was.

Over \$4,400 was raised for the NJ APDA, thanks to all those who gave generously of their time and effort. Allan believes that it is only through the commitment, generosity, and support of family and friends working with organizations like the APDA to fund research and education, that a cure for PD will be found.



"Alan Freed... meet Allan Bleich."

Ragone and Kortman Families

Special recognition and gratitude go to the Ragone and Kortman families for participating/contributing to *every* one of our NJ APDA 2009 fundraising activities.



*Thank you to our
2009 Event Sponsors!*

***The NJ APDA Chapter gratefully acknowledges the following
corporations and individuals for their substantial contributions to our
2009 fundraising events:***

***Affinity Federal Credit Union, Basking Ridge, Cedar Knolls,
Flemington, Hillsborough, and Piscataway***

Allan Bleich Family & Friends

Branchburg Family Golf Center – Branchburg

Mr. Dennis Carroll

Herr Foods, Inc - Somerset

Investrio Stock Selector Fund - Ringoes

Learning Express, Branchburg, Bridgewater, Edison, Gillette, Hillsborough, Westfield

Macy's, Bridgewater Commons Mall

Mary Kay Cosmetics, Somerset

Massage Envy, Branchburg

NJ Freemasons, 10th Masonic District, Plainfield

PD Talks, Ontario, CA

Spooky Brook Landscaping and Nursery, Somerset

The Ragone and Kortman Families

Ms. Betty Ann Richter

The Sequeira Family

Ms. Andrea Some

Ultimate Collision Repair, Edison

*Continued from page 1****Are there side effects to DBS?***

Just as there are symptoms for which DBS is not effective, there are also symptoms DBS may make worse. Dysarthria or speaking difficulties is typical in PD and is characterized by a reduced loudness and monotone pitch. DBS can exacerbate the dysarthria, making it difficult to communicate. Mental status becomes affected in the late stages of PD, and if already in a fragile state, DBS may have a detrimental effect.

What is the time course of DBS treatment?

DBS as a treatment is an ongoing therapy and not a single surgical event. The process occurs in four basic phases: 1) Candidacy assessment, best done by a multidisciplinary team involving the neurosurgeon, a neurologist who is movement disorder specialist, a speech therapist, physical therapists. 2) Surgical procedures, best done in two stages, the first involving the implantation of the electrodes, during which the patient assists in guiding the exact placement by their awake responses to test stimulation, and the second implanting the internal pulse generator or battery under the skin of the upper torso. 3) Initial programming of stimulation parameters occurs over approximately six months, during which the clinician programmer together with the neurologist optimize the stimulation settings and the different medications and their doses. 4) Periodic, annual or semi-annual long term maintenance over the course of the DBS treatment.

How does one seek out more information on DBS?

Once an individual decides to investigate DBS adjunctive therapy, they can initiate the process by obtaining a referral from their neurologist to a center that performs DBS. Robert Wood Johnson University Hospital has a multidisciplinary DBS team. Movement Disorder clinics are held twice a month on the fourth floor of the Clinical Academic Building 125 Paterson Street. Appointments can be made by calling (732) 235-7757.



**For additional educational
information on
Deep Brain Stimulation**
Go to:
<http://www.dbs-stn.org>

**If a fall happens.....**

David C. King, PT, MS
Kessler Institute for Rehabilitation

So you did everything right. You wore shoes with forgiving soles. You did your exercises and trained your balance as best you could. You were careful about taking your medications properly. Yet somehow you've taken a tumble. How you act now is very important. If you've thought about it in advance recovering from a fall can be a calm and safe experience, but a lack of preparation can lead to panic and possibly an injury that didn't need to happen.

Don't rush to get up

First rule, "Do not rush to get up". Unless you've fallen in a mud puddle or the middle of traffic there is no need to rush. You're on the ground, you can't fall again. It would be better for you to catch your breath, make sure you are unhurt and then do what needs to be done to get up. There is no need to feel embarrassed, but if you do, it is better to suffer a little embarrassment than to hurt yourself by rushing to get up.

Know what you will say

If you've fallen in a public place there is a good chance that someone is going to try to yank you to your feet. This is when you should remember the phrase that pays, "Thank you for coming, please let me catch my breath, and then please help me up". This will let your rescuer catch their breath and think about how to safely help you up rather than yanking your arms out of their sockets.

Keep calm, no shouting aloud

You and many people around you will feel that shot of adrenaline. But you need to keep things calm so people can think about safety. If you are calm it can have a calming effect on others. If someone is a bit panicked and their voice is raised it can quickly spread to others including your spouse and loved ones. So if someone in the area has raised their voice you can reverse the situation by keeping your voice calm and suggesting that everyone stop to take a breath.

Make sure you are not hurt

Take just a minute to feel your body, look for any wounds, and make sure that the legs you are going to try to stand on again are unhurt. The shock of falling may momentarily mask any pain so take a second to see that you are ok. And if an injury is discovered, again try to keep things calm.

Continued on page 6



Continued from page 5

If you're the person's spouse or friend

First, all of the above applies to you as well. Don't rush the person who's fallen to get up too soon.

Be ready to address others who are moving too quickly – again the phrase that says “Please let us catch our breath, and then please help me get him/her up”. Be calm, keep your voice calm but do assert yourself if necessary – don't let others argue. Keep your instructions simple and give them one step at a time. Make sure the person is unhurt.

1. Ask the person who has fallen “Do you hurt anywhere”?
2. Instruct the person to move different parts of their body while observing for the following signs:
 - Ø Inability to move
 - Ø Guarded movement
 - Ø Facial grimacing
 - Ø Other body language which may be associated with discomfort
3. Inspect any area that is painful for bleeding or obvious fracture
 - Ø If a fracture is suspected, do not move the person
 - Ø If bleeding is present, apply pressure over the source
4. To decrease the risk of injury
 - Ø Allow the person to move independently as much as they are able
 - Ø If possible bring them a chair to use as an assistive device to get up
 - Ø Ask the person to first come to a sitting position and rest in this position before attempting to get up.

Preparedness helps

There are several ways to be prepared for a fall. First is to have the ability to call for help if you are home alone. Personal Emergency Response Systems (PERS) the famous “I've fallen and can't get up” buttons are a good idea to have if you are at risk for falls. In my years as a therapist I have treated several individuals who fell at home and spent several days alone on the floor unable to call for help. A simple button worn like a watch or pendant would have helped them tremendously.

Having your phone accessible from the floor can help. If you are unable to rise but able to crawl, a phone on a bed side table or desk top may be in reach when a wall mounted phone may be too high.

Keeping a cell phone with you can be a great relief.

Making neighbors aware of an individual's frailty is important. I have asked my father's neighbors to go knock on his door if he fails to pick up his newspaper from the driveway. And two neighbors who are long time friends have his door key. Letting your neighbors read this article would be a good idea too.

9-1-1

It is ok to dial 9-1-1 for help after a fall. In some areas a police car may be sent around and in others a paramedic may respond. Most emergency responders are more than happy to be of help to someone who has fallen. If you think you or your spouse may be injured in an attempt to get off the floor a call for help is prudent.

While I hope you never have to use the instructions above it is important to think about how to act in an emergency before it occurs. Please share these thoughts with others who may be around you at a time of need.

While I hope you never have to use the instructions



CHECK OUT OUR WEBSITE!

www.njapda.org

LEARN ABOUT

Upcoming Events

Support Groups

Order Free Literature

How to Donate

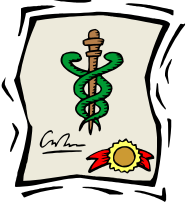
****Now, View the 2009 Conference**

Speaker Presentations Online

PD Research News

Volunteer Opportunities

And More!!



Bladder Problems in Parkinson's Disease

**Hari Tunuguntla, M.D., M.Ch., Assistant Professor, Division of Urology
Director, Neuro-Urology, Voiding Dysfunction, Reconstructive Urology &
Female Urology, UMDNJ-Robert Wood Johnson Medical School**

Parkinson's Disease (PD) is a progressive and degenerative disorder of the central nervous system, characterized by tremors, sluggishness, rigidity of muscles, impaired mobility, difficulty sleeping, and disturbance of autonomic nervous system that can manifest in the form of urinary frequency, urgency, leakage of urine (rarely, inability to pass urine), and constipation.

Question. How does one urinate normally? How is the normal process of urination controlled by the brain?

Answer: Normally, the bladder is in an *off* condition from the neurological standpoint and in this condition, it is relaxed while filling with urine. When the bladder becomes full, the brain is alerted and under socially acceptable circumstances, the brain signals the bladder to turn *on* (contract) to release urine.

Question. Why does the urination get affected in Parkinson's patients?

Answer: Cells in the portion of the brain associated with urine control produce a chemical called *Dopamine*. Its release helps to keep the bladder in the *off* condition during urine storage and prevents the bladder from contracting. In Parkinson's disease, these cells are lost or reduced in number resulting in bladder on and off problems. This manifests as urinary disturbances in these patients.

Question. How does the bladder control problem present in Parkinson's disease?

Answer: The following are the manifestations of abnormal urinary control:

Overactive bladder (urinary urgency and urge incontinence; usually with increased frequency of urination and increased urination during night)

Urge incontinence (sudden loss of urine as the result of overactive bladder)

Not able to urinate at all

Nocturia (frequent night time waking up from sleep to urinate).

Question. Can other problems of urination influence urination in Parkinson's disease?

Answer: Yes. Bladder control in Parkinson's patients may be further complicated by the enlarged prostate in men urethral leakage due to urethral or pelvic muscle deficiency in women.

Question: Can Overactive Bladder occur in Parkinson's patients?

Answer: *Overactive bladder* (OAB) occurs when the muscles of the bladder involuntarily contract more often than normal and at inappropriate times, usually when the bladder is only half full instead of three-quarters or more.

Your mind reads those contractions as an urgent need to urinate. In *dry* OAB, you will make it to the bathroom in time but not without worry and anxiety. On the other hand, in *wet* OAB, you may not always make it without peeing on yourself (leaking urine).

OAB is of 2 types: neurogenic and idiopathic (non-neurogenic). Parkinson's disease is an important cause of neurogenic OAB. Other causes of neurogenic OAB include multiple sclerosis and stroke, nerve damage caused by injury to the abdominal area, pelvis or previous surgery.

Question. Are there any other conditions that manifest with symptoms of OAB?

Answer: . Yes. These include:

1. Side effects from medications such as diuretics (water pills) and caffeine-containing medications
2. Urinary tract infection
3. Tumors or other abnormalities in the bladder such as bladder cancer
4. Occasionally, stones in the bladder
5. Inflammation of the prostate in men
6. Bladder outlet obstruction due to previous surgery for urine leakage

Continued on page 8

Continued from page 7

Bladder Problems and PD

When you see the physician with symptoms suggestive of OAB, the physician performs certain tests (urine analysis, culture/sensitivity, cytological examination of the urine, general medical check up, digital rectal examination) and procedures (*cystoscopy* [looking inside the bladder with a thin telescope with light], and *urodynamic* examination) to exclude the abovementioned conditions. Treatment of the above conditions resolves symptoms presenting as OAB.

Q. How are the bladder problems in patients with Parkinson's disease treated?

Answer: The treatment options include dietary changes, bladder training (timed and double voiding), medications (that relax the bladder), minimally invasive procedures (instillation of medications inside the bladder, and as a last resort, surgery (increasing the bladder capacity by incorporating a portion of the patient's own gut; creating a permanent opening of the bladder to the abdominal wall skin; removing the whole bladder with replacement of the bladder by a portion of the patient's own intestine).

A new treatment option for the bladder management in Parkinson's patients is the injection of *botulinum toxin* into the bladder muscle by means of a thin needle inserted through a telescope passed into the bladder through the urethra. This treatment is currently not approved by the FDA for this indication. However, clinical trials all over the world including the US have demonstrated its efficacy. Parkinson's patients with urinary urgency and leakage that are refractory to medications may now be enrolled in a clinical trial to undergo this treatment. The effect of this treatment lasts about 4-6 months and treatment needs to be repeated for the continued benefit.

All the abovementioned treatment options are available in major hospitals and medical institutions like Robert Wood Johnson University Hospital, New Brunswick, NJ. For appointments with Dr. Tunuguntala, please call 732-235-7775.

WEBSITE TO CHECK OUT!

www.patientslikeme.com/parkinsons/

RESEARCH ON MEMORY, MEDICATION AND PARKINSON'S DISEASE AT RUTGERS-NEWARK

Professor Mark. A. Gluck, co-director of the Memory Disorders Project, at the Aidekman Neuroscience Center at Rutgers University-Newark seeks patients with Parkinson's disease to participate in research studies designed to improve our understanding of the disease and its treatment. The studies can be conducted either at Rutgers-Newark or in people's homes in the greater NJ/NY region.

The project is part of an ongoing NIH-funded investigation of cognition, attention, and memory function in patients with Parkinson's disease, with a particular focus on better understanding the role of dopaminergic medication and how this interacts with the disease. The long-term goal is to develop treatments for the disease which optimize both the patient's motor skills and cognitive and memory function.

For these studies we are interested in recruiting individuals with mild-to-moderate Parkinson's disease. In addition to administering a comprehensive neuropsychological evaluation, participants will be asked to perform various computer "games" which are designed to evaluate specific cognitive and memory capabilities in Parkinson's patients.

Participants in our studies will be paid \$20/hour. For more information on these studies and how to participate, please contact our research coordinator, Lisa Haber-Chalom, either by phone at (973) 353-3668 or via email at lhchalom@andromeda.rutgers.edu.



"Parkinson Disease Impersonators (Look-A-Likes) of PSP, CBD & MSA"

Webinar Sponsored by
Cure PSP

Speaker: Dr. Ronald Ziman

Thursday, Jan. 28, at 8:00 p.m.

To register, go to:

<https://www2.gotomeeting.com/>
or email Coordinator@gmail.com.



Caregiving & Parkinson's Disease

Jill Friedman, Ph.D.

Department of Psychiatry, UMDNJ-Robert Wood Johnson Medical School

“The longer I am a caregiver, the more I realize that it is essential to understand yourself and what your needs are – what satisfies you – what kind of behaviors make you angry – what makes you happy and thus more patient? Why is this important and why should we be thinking about ourselves and not trying to better understand the person who has the disease? Caregivers also ‘have’ Parkinson’s disease – but in a very different way. The caregiver and their loved one are in this journey together and anything that can make things better for both is worthwhile pursuing” (Susan Hamburger, 2003-2009, MyParkinsons.org).

Who are Caregivers?

If you are helping to care for a loved one with Parkinson’s disease, you are a caregiver. Caregivers are family members or friends. They may live nearby or far away. You may not think of yourself as a caregiver, as you may see what you are doing as something natural.

What is the role of the caregivers?

Caregivers provide important and constant physical care for their loved ones. There are many different ways to be a caregiver. Caregiving can mean helping your loved one with day-to-day activities, like buttoning their shirt, preparing meals, or helping out with the checkbook. Caregiving can also mean being supportive in helping the person cope with feelings that emerge during this time.

Is Caregiving all stressful?

Caregiver stress involves the emotional and physical strain of caregiving. While caregiving can be challenging, it is important to note that it can also be rewarding. However, it is important that you take care of yourself so that the experience of caregiving does not feel entirely stressful.

Why does caregiving feel difficult?

Caregiving for a loved one who is ill is a challenge. It is normal to experience a wide range of emotions. For example, you may feel scared, **angry**, sad, or lonely. Be mindful that these signs may signify stress-overload, as these symptoms may affect your ability to care for your loved one and may affect the way in which you interact with your loved one.

Should I educate myself about Parkinson’s disease?

Knowing as much as you can about the disease and care

strategies will prepare you for the Parkinson’s journey. Understanding how Parkinson’s affects your loved one will help you adapt to the changes.

Scheduling time for yourself:

Your health is important. Caregiving can feel like a full-time job. Caregiving can be even more challenging if you have other responsibilities, such as working, raising children, and taking care of your own health. Sometimes, caregivers can ignore their own needs. It’s important to take care of yourself, so as to replenish your energy and patience. Schedule “alone time” in which you have a life away from Parkinson’s disease. This is essential for your emotional well-being. Visit friends and family and pursue your interests, even if it is for a short time per day.

Ways to engage in take care of yourself:

- Ask for help from your healthcare team, friends, and family.
- Stay active
- Pay attention to what you’re eating
- Say “no” when you need to.
- Set goals for yourself so that you become proactive rather than reactive.
- Get enough sleep and rest regularly
- Accept that there may be times when you feel discouraged, resentful, or guilty.
- Keep up with your own check-ups, screenings, and medications.
- Take a break
- Be aware of your limits

But, is it okay to give myself a break?

Again, it is recommended to schedule time for yourself. Your individuality is important.

Trying these tips, for example, is in your best interest:

- Go to a movie or concert
- Have a meal with friends
- Read a book or write a journal
- Take a walk
- Pursue a hobby
- Take a long bath
- Listen to relaxing music
- Try yoga or other relaxation technique

Continued on page 11



*Upcoming Educational Events and
RWJUH Support Group Meetings
January-April 2010
www.njapda.org*

RWJUH Parkinson Support Groups

Afternoon Meetings

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

Time: 12:30 PM

Place: Auditorium

RWJ University Hospital, New Brunswick, NJ

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

Thursday, January 21, 2010

Topic: Mood and Stress
Management in the New Year
Speaker: Dr. Jill Friedman
UMDNJ-RWJMS

Thursday, February 18, 2010

Topic: Open Discussion Meeting

Thursday, March 18, 2010

Topic: Preventing A Fall with Parkinson's
Speaker: Debbie Caputo, NP,
UMDNJ-RWJMS



Evening Meetings

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

Time: 7:00 PM

Place: Auditorium

RWJ University Hospital, New Brunswick, NJ

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

Wednesday, January 20, 2010

Topic: Mood and Stress Management
in the New Year
Speaker: Dr. Jill Friedman, UMDNJ-RWMS

Wednesday, February 17, 2010

Topic: Open Discussion Meeting
**Please note at this meeting, caregivers and
families will break into separate rooms.

Wednesday, March 17, 2010

Topic: Ask the Nurse Practitioner
Speaker: Debbie Caputo, NP,
UMDNJ-RWJMS



Save the Date

**Strike Out Parkinson's
Bowl-a-thon!**

The NJ American Parkinson Disease Association Chapter will hold a bowl-a-thon on Sunday, March 21, Location: Central New Jersey. Join us for fun and camaraderie. More details to follow online at www.njapda.org in January and the February newsletter.

Excellence in Service Award

We are accepting nominations for the 6th Annual Excellence in Service Award. You may nominate an individual who is active in the Parkinson Community. Examples include a support group facilitator, volunteer, caregiver, or person with Parkinson's who is an inspiration to others and Parkinson advocates. **Please no political officials. Submissions are due by Friday, Feb 5, 2010.**



Caring for a Loved One With Parkinson's Phone Support Group:

This series conveniently meets by telephone! "Meeting" Monday evenings at 7:30 PM on **April 19-May 17, 2010**. This is an opportunity to join with other people to share and discuss issues related to Parkinson's. Experts in the field will join each week. The group is for **caregivers only**. Elizabeth Schaaf will facilitate the series. Total cost: \$25.00. Guest speakers: to be announced. For more info, to register, call **DOROT's Caregivers' Connections at 877-819-9147**.



**Annual People with Parkinson's
and Family Conference**

Annual educational symposium on **Saturday, April 10, 2010 at the Imperia, Somerset NJ**, 9:30 AM to 3:15 PM. Featuring Speakers: Dave Iverson, Dr. Claire Henchcliffe and John Argue. More details to follow!

Parkinson's Unity Walk

April 2010. (date to be confirmed shortly) NYC's Central Park. Please call toll free: 1-866-PUW-WALK (1-866-789-9255), fax: (609) 688-0875.; Website: www.unitywalk.org.



Continued from page 9**How do I set priorities and adjust expectations?**

- Do the important things on your list first
- Forgive yourself if you don't do things the way you used to/less perfectly
- Try to be grateful that your loved one will forget an oversight

COPING**I find that I cope in different ways**

Being a caregiver can be challenging and overwhelming. The way in which we cope with situations is in our control. It is important to be aware of mechanisms to help cope with situations when they arise.

Psychologists have studied two effective methods of coping with stress. These include problem-focused and emotion-focused coping. Problem-focused methods involve efforts to alter or eliminate the problem. These include confronting the problem, engaging in problem solving, and seeking social support. Emotion-focused methods are aimed at regulating the negative emotional consequences of the stressor. Examples include processing and talking about how we feel, trying to put the problem in perspective, and limiting the time spent in negative thinking.

As a caregiver, for example, you may desire "me" time. A problem-focused way to cope with seeking "me" time may entail calling other family members or friends to see if someone can help you out. Should you be unable to find anyone to take your place while you engage in "me" time, it is normal to feel frustrated, irritated, resentful, etc. Instead of letting these emotions get you down, this may be a good time to engage in emotion-focused coping. Ways to engage in emotion-focused coping include, but are not limited to the following: engaging in positive self-talk ("I can't find someone else now. But, there will be other times when I will be able to find "me" time. Maybe I can think of something relaxing to do with my loved one"); engage in relaxation and/or meditation exercises, and call a close friend or family member and express your frustration.

People use a mixture of these different of these different types of coping styles. The way one copes typically depends on the situation.

Being Positive:

Your attitude can make a difference in how you feel. Focusing on what your loved one can do, as opposed to that which he or she is unable to do, can make things easier. While Parkinson's is a serious disease, maintain a sense of humor, which is a good coping strategy.

Long-Distance Caregiving:

When someone you love is diagnosed with a major medical condition, the distance can seem difficult to overcome. Modern means of technology (i.e., cell phones, internet, and

movie-phones) can help make it easier to stay interconnected.

Tips for Long-Distance Caregiving

- Focus on what you can do
- Make the most of your visits
- Meet with some of your loved one's support network
- Plan visits to coincide with medical appointments

Plan for the future:

While your loved one is still capable, review his or her financial situation. Consider future health and personal care decisions. Discuss legal and estate planning. Brainstorm a backup caregiving plan in the event that you are unable to provide care in the future.

Finding Additional Help*Psychotherapy/Psychoeducational Interventions*

Stress related to caregiving is normal. If it is not addressed, then these emotions can lead to severe physical symptoms that affect your health.

Talk to a counselor, psychologist, or other mental health professional if you are feeling stress and overwhelm.

Should I join a support group?

Support groups can be helpful for many caregivers, as talking with other caregivers can help you to feel less alone. With modern technology, support groups are not only held face-to-face, but also are held over the telephone and via online support groups. These groups allow you to share your worries and concerns. Furthermore, these groups allow you to interact with others in similar situations.

To find a support group in your area, you can check with:

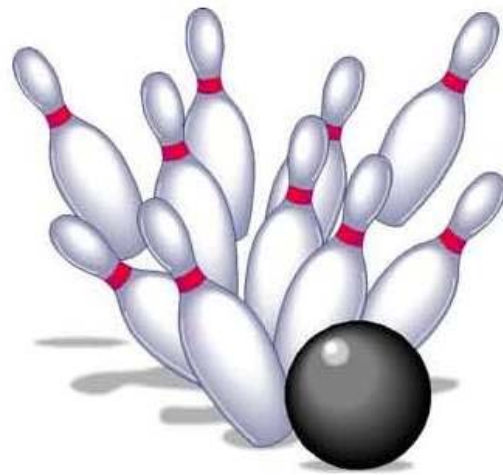
- Your loved one's physician
- Social Workers
- Local Hospitals
- The phone book
- Community calendars in local newspapers and magazines
- Web sites of national organizations like the National Parkinson Foundation; the Parkinson's Disease Foundation; the American Parkinson Disease Association; and the Michael J. Fox Foundation.

**What caregiving services can I find in my community?**

- Transportation
- Meal delivery
- Home health care services (nursing, physical therapy)
- Non-medical home care services (housekeeping, cooking, companionship)
- Home modification (changes to the home to make it easier for your loved one to perform activities of daily living)

How can I find out more information?

For additional information about coping with caregiving and psychotherapeutic treatment resources in the community, contact Dr. Jill Friedman at 732-235-4160, or consult your local physician.



**SAVE
THE
DATE!!**

**Strike Out Parkinson's
bowl-a-thon fundraiser
Sunday, MARCH 21, 2010**



ROCK STEADY

"It's not the type of person I believe in. I'll be and let things happen," says Bob Benjamin. "I'll even do some thing, I do it."

In 1996, Benjamin, then 36, was diagnosed with Parkinson's disease. True to his credo, he established the Light of Day Foundation, which holds benefit concerts to raise awareness of Parkinson's as well as funds to fight it and related illnesses.

It all began just before his 35th birthday party with a simple request for Parkinson's donations rather than personal gifts. Benjamin raised \$2,000 with that first night of music. The concerts were because an annual event, with the first official show taking place in 2000 at the Stone Pony in Asbury Park. A well-connected music industry veteran and artist manager, Benjamin was able to get some big names behind his efforts, including a few surprise visits from grand old friend Bruce Springsteen. The two have been close since Benjamin's self-diagnosed crazy days had a chance meeting with Springsteen during the 1970s rock-and-roll scene.

In fact, the foundation's name is inspired by the Springsteen power anthem "Light of Day." The band has been a presence at many of the shows, offering the all-too-appropriate lyrics: "Well I'm a little down under, but I've got my eyes on a star that's shining the way I'm just around the corner to the light of day."

Other performers have included Joe Gradowky, Jakob Dylan, Lucinda Williams, and New Jersey's own Steve, Southside Johnny, and Joe Piro, as well as actor (and Parkinson's sufferer) Michael J. Fox, who starred in the film *Light of Day*.

The Light of Day concerts now rock out in eleven countries, and the foundation has raised more than \$1 million. "I don't charge my attention," Benjamin says, "but I can raise as much money as I can."
—JANEY FARRERTY

BOB BENJAMIN
Highland Park
Founder and president, the Light of Day Foundation

**2009 Seeds of Hope Honoree
Bob Benjamin**



Bob Benjamin, founder of Light Of Day Foundation, has created a grassroots organization that has raised more than a \$1,000,000 to help find a cure for degenerative neuromuscular diseases such as Parkinson's disease. Benjamin himself was diagnosed with Parkinson's 12 years ago. In addition to raising money, the organization also raises awareness through approximately 20 fundraising concerts and events in Europe, Canada and the U.S. The long list of musical participants includes New Jersey's very own Bruce Springsteen.

Light of Day New Jersey - 10th Anniversary! Show dates will be January 16 and January 17. Please go to www.lightofday.org for more details.

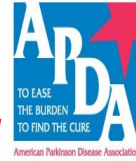
Bob Benjamin (picture on left) was spotlighted in the August edition of the NJ Monthly magazine.



**NJ Chapter American Parkinson Disease Association
2009 – 2010 Membership Application/Renewal**

DUE BY DECEMBER 31, 2009

Our Chapter depends on your Annual Membership dues and other donations throughout the year to help fund Parkinson's disease educational programs, support, and research initiatives.



The NJ chapter membership/fiscal year begins September 1st and ends August 31st.

The annual recommended membership dues: **\$20 individual or \$35 per household.**

Please fill out the information below, make checks payable to **APDA NJ Chapter** and mail to:

**NJ American Parkinson's I and R Center; 120 Albany Street, Suite 360;
New Brunswick, NJ 08901**

New Member: _____ Renewing Member: _____ Date: ____/____/2009

Last Name: _____ First Name: _____

Additional Name(s):

Address:

City: _____ State: _____ Zip: _____

Telephone #: _____ E-Mail: _____@_____

Please include my email address on your event and news distribution list:

- Yes**
- No thanks.**

We understand that some individuals cannot afford the full cost of membership dues.

What membership amount would be reasonable for you to pay? \$_____

Are you interested in volunteer opportunities with the Chapter? If so, please check applicable area(s) below and you will be contacted by a Board Member with more details.

- | | |
|--|--|
| <input type="checkbox"/> General Assistance | <input type="checkbox"/> Fundraising |
| <input type="checkbox"/> Publicity | <input type="checkbox"/> Event Planning |
| <input type="checkbox"/> Advocacy | <input type="checkbox"/> Membership |
| <input type="checkbox"/> Other _____ | |

For office use only: check# _____ cash \$: _____ membership: I or F date : _____ initials: _____



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, Wykoff, NJ 07481

Meetings: Monthly, 1st & 3rd Thursday

1st Thursday: separate caregiver & PWP meetings

3rd Thursday: Guest speaker; no speakers Jul, Aug, Dec

Time: 7:30 p.m.

Contact: Eugene Provost (973) 362-0440

Northern Pascack Valley Support Group

First Congregation Church-Lower Level

276 Haworth Ave, Haworth, NJ 07641

No July or August Meetings

Meetings: Monthly, 1st Saturday

Time: 12:15-1:00p.m. Yoga

1:00 p.m. Speaker/Rap Session, Social.

Contact: Joe Capuzzo (201) 261-0240

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: Kevin X. Kyle (201) 747-9096

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: 7:00 p.m.- 8:30 p.m.

Contact: Myra Hirschhorn, (609) 914-8082

CAMDEN COUNTY

NO ACTIVE SUPPORT GROUPS

CAPE MAY COUNTY

Victoria Commons

610 Town Bank Road, North Cape May, NJ 08204

Meetings: Monthly, 2nd Thursday

No July or August meetings

Time: 1:00 p.m.

Contact: Rita Tumas (609) 886-2455

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

Virginia (862) 210-8388

Exercise Group:

Congregation Beth Ahm, 56 Grove Ave, Verona

Classes: Every Monday, 10:30 a.m.

Contact: Bill Gleason (973) 403-1294

GLOUCESTER COUNTY

Southern New Jersey Support Group

Woodbury Mews

122 Green Avenue, Woodbury, NJ 08096

Meetings: Monthly, 1st Wednesday

No July meeting, No regular October meeting

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

Contact: Diane Gruszewski (609) 254-3096

Caregiver Parkinson's Support Group

Deptford Library, 670 Ward Drive Deptford NJ 08096

Meetings: Monthly, 4th Wednesday

Time: 10:30 a.m. to 12:00 p.m.

Contact: Grace Ravolli (856) 848-3450

HUDSON COUNTY

NO ACTIVE SUPPORT GROUPS

HUNTERDON COUNTY

Division of Senior Services Office on Aging

Route 31, Flemington, NJ 08822

Meetings: Monthly, 4th Friday

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

Contact: Barbara Burgard (908) 788-6401 (ext 3149)

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. to 3:00 p.m.

Contact: John Wicoff (609) 737-3364

MIDDLESEX COUNTY

RWJ University Hospital, Auditorium

1 RWJ Place, New Brunswick, NJ 08901

Contact: Elizabeth Schaaf (732)745-7520

Young Onset Patient & Family Support Group

Meetings: Monthly, 3rd Wednesday

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

Later On-Set Patient & Family Support Group

Meetings: Monthly, 3rd Thursday

Time: 12:30 p.m. to 2:00 p.m.



New Jersey Parkinson's Support Groups

MIDDLESEX COUNTY continued

New Jersey Neuroscience Institute

Rehabilitation Medical Conference Room,
65 James Street, Edison NJ, (732) 321-7010; extension 68726

Contact: Jacqueline Cristini, JCristini@Solarishs.org

Early Onset Patient & Family Support Group

Meetings: Monthly, 1st Wednesday

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

Parkinson's Patient & Family Support Group

Meetings: Monthly, 4th Thursday

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

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 YMCA

111 Kings Road, Madison, NJ

Meetings: Monthly, 2nd Tuesday

Time: 1:00 p.m.

Contact: Carol Carlson (973) 627-4087

Care One at Livingston Caregiver Support

76 Passaic Ave, Livingston, NJ

Meetings: Monthly, 1st Monday

Time: 1:00 p.m. **Contact:** Carol Carlson (973) 627-4087

Parkinson's Exercise Program @ Madison YMCA

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

Contact: Susan Sheeley (973) 822-9622

76 Passaic Ave, Livingston, NJ

Meetings: Monthly, 1st Monday

Time: 1:00 p.m. **Contact:** Carol Carlson (973) 627-4087

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: Susan Delmar or Gabriel White (732) 836-4007

OCEAN COUNTY (continued)

Parkinson's Support Group Meeting

Ocean Medical Center Brick Hospital

425 Jack Martin Blvd, Bricktown, NJ 08724

Fourth Friday of month; call first for details

Time: 2:00 pm-3:00 pm.

Contact: Donna Whitney (732) 836-4614

PASSAIC COUNTY

Our Lady Queen of Peace Church (Annex)

1911 Union Valley Rd, Hewitt NJ 07421

Meetings: Monthly, 3rd Sunday

Time: 2:00 p.m.

Contact: Deacon Dave Cedrone (973) 728-8211)

Website: www.olqp-pdsupport.org

Email: info@olqp-pdsupport.org

Preakness Healthcare Center

Unit 3, 305 Oldham Rd, Wayne NJ 07470

Meetings: Monthly, 3rd Thursday

Time: 12:00 noon

Contact: Mike Patterson (973) 904-3979

MGP3737@hotmail.com

SALEM COUNTY NO ACTIVE SUPPORT GROUPS

SOMERSET COUNTY

Fellowship Village (Grill Room)

8000 Fellowship Road, Basking Ridge, NJ 07920

Meetings: Monthly, 3rd Tuesdays (No Jul, Aug, Nov, Dec) **Time:** 1:30-3:00 p.m.

Contact: Maria Santo (908) 580-3836

SUSSEX COUNTY (see Passaic-Hewitt)

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

Heath Village

430 Schooley's Mountain Rd, Hackettstown 07840

Meetings: Monthly, 2nd Monday; **Time:** 6:30-7:30 p.m.

Contact: Jill Mutek, (908) 684-5214;

Valerie Perry (908) 684-5202

PSP SUPPORT GROUP

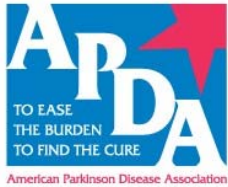
RWJ University Hospital, MEB Room #108A

1 RWJ Place, New Brunswick, NJ 08901

Meetings: Monthly, last Saturday of the month

Time: 10:30 a.m. (**First meeting: Sept 26, 2009**)

Contact: Dee Gozonsky (609) 918-0072



SAVE THE DATES

Strike Out Parkinson's Bowl-a-thon!

Sunday, March 21, 2010

Location: To Be Announced

1:00 PM to 4:00 PM

More details coming up in January online at www.njapda.org and details in February Newsletter

Annual People With Parkinson's and Family Educational Conference

Saturday, April 10, 2010

9:30 AM to 3:00 PM

The Imperia, Somerset, NJ

More details February Newsletter

Parkinson's Unity Walk

April 2010 (3rd or 4th Saturday in April)

New York's Central Park

More details February 2010 Newsletter

<http://www.unitywalk.org>

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 & Referral Center

Elizabeth Schaaf, MBA, CHES

Coordinator & Editor
NJ/APDA Parkinson Disease Information and Referral Center & Coordinator, Community Education Department, RWJUH

(732) 745-7520

(732) 745-3114-fax

Elizabeth.schaaf@rwjuh.edu

Kathleen Johnson

Assistant Coordinator,
Community Education Department
(732) 418-8110

Kathleen.johnson@rwjuh.edu

Vicki Collier

President
NJ Chapter American Parkinson Disease Association
njapda@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

120 Albany Street, Suite 360
New Brunswick, NJ 08901
(732) 745-7520
(732) 745-3114-fax



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 _____

Address _____

Old Address (if applicable) _____

Phone _____

Email _____