



# The Parkinson's Bulletin

June-August  
Summer 2009



*The NJ/APDA Parkinson Disease  
Information and Referral Center*  
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[www.njapda.org](http://www.njapda.org)

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## Advances in Gene Therapy for Parkinson's Disease

*M. Maral Mouradian, MD*

*William Dow Lovett Professor of Neurology*

*Director, Center for Neurodegenerative and Neuroimmunologic Diseases, UMDNJ – RWJMS*

Gene therapy is an experimental approach to deliver genetic material (DNA) that is believed to provide benefit for certain diseases. DNA contains the code that translates into the production of specific protein molecules, which in turn carry out the functions of the cells in our body and help maintain their survival. Since simply injecting a piece of DNA is incapable of producing the protein end product, scientists typically package the DNA segment of interest in an otherwise disabled virus. Such modified viruses are called viral vectors. A viral vector utilizes its own machinery to make protein from the human DNA that scientists insert into the virus but is stripped of its ability to cause disease

The field of clinical gene therapy is about twenty years old with many more years of experiments in laboratory dishes and animals prior to that. The first human trial took place at the National Institutes of Health Clinical Center in 1990 in children with an immune deficiency due to a genetic mutation. A normal copy of the defective gene was delivered into these patients. Since then, small steps forward as well as serious setbacks have led the field to a stage where a large number of experimental gene therapy trials are currently underway for various health problems.

Among neurologic conditions, Parkinson's disease (PD) has long been considered a model disease for gene therapy. This is because 1) the pathology in PD is relatively localized to the substantia nigra in the base of the brain at least in the early stages of the disease, 2) we have a good understanding of how dopamine is made and handled by the brain, 3) we know of nutrient molecules that help dopamine producing neurons (brain cells) survive, and 4) because we have animal models of PD that can be used for testing new treatment approaches before going to patients. In addition, the discovery in the past dozen years of several genes responsible for inherited forms of PD made it possible for researchers to think about delivering normal copies of some of these genes as a reasonable strategy in certain patient groups. Parallel with these developments in PD, improvements in viral vector designs have made it possible to deliver genes directly into the brain with reasonable safety.

With this background knowledge and after nearly two decades of experiments with various gene delivery approaches in animal models of PD including rodents and monkeys, clinical trials are finally underway under

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**Visit our NJ APDA website for up-to-date information on programs, special events, and available resources:**  
<http://www.njapda.org>



## Information and Referral Center Coordinator's Corner, Elizabeth Schaaf



*Dear Friends,*

The Summer season is upon us, and I wanted to take a moment to reflect on our spring Parkinson's awareness

activities.

The NJ APDA Chapter held its first Strike Out Parkinson's Bowl-a-thon on Sunday, March 22 at Brunswick Zone in North Brunswick. It was a successful and fun event. We are pleased to announce that we raised over \$6,000 for the NJ APDA Chapter. Thank you for all who attended and supported this event. We hope to hold our next Bowl-a-thon in the Winter or Spring of 2010.

On April 4, we held our Annual Spring Living Well with Parkinson's Symposium at The Imperia in Somerset, New Jersey. Topics included Medical Management with Fiona Gupta, MD (Hackensack University Hospital); PD Plan for Life with Jean Burns and Sheryl Jedlinski (People with PD); Resilience and PD with Dr. David Rintell (Brigham's and Women's); 2009 Unity Walk with Stacie Mishler; Environment and PD with Mona Thiruchelvam, PhD (UMDNJ and Rutgers University). For those of you who were unable attend, we will have DVD copies of the conference available

for loan in late June. First preference will be given to those who were unable to attend the April 4 conference.

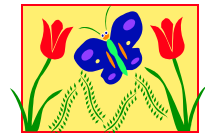
I want to take this opportunity to thank so many for your thoughtfulness and generosity during the Spring Symposium. It meant so much to me.

Please see page 12 for our summer and fall programs. Please note that we are having a conference in Teaneck NJ on October 10. Our South Jersey conference will be held on November 14 in Voorhees, NJ. Please save the date(s).

The NJ APDA I and R Center and the NJ APDA Chapter wish you a happy and safe summer. We hope to see you very soon.

*Kind Regards, Elizabeth Schaaf*

## April 4, 2009 Conference-Special Thanks To:



### Staff

Kathleen Johnson  
RWJUH, Assistant Coordinator  
Community Education Department

### Volunteers

Barbara Vecchiarelli, Sheila Aronberg, Anne Dalin (photographer) Debbie Hargiss, Karen Powers, Dick Powers, Vicki Collier, Claire Salamon, Marilyn Schaefer, Bill Collier, and Barbara Tanz.

***Claire Salamon, Bill Collier and Vicki Collier. secured all of the wonderful door and gift certificates.***

***Thank you!!***

### Conference Sponsors

Boehinger Ingelheim, Ipsen, Medtronic, NJ Chapter American Parkinson Disease Association, Teva Neuroscience.

### Conference Exhibitors

A Healing Touch and Wellness Center, Beads for Parkinson's Research, Jersey Coast Chapter of American Red Cross, Buckingham Place, Healthcare Depot of Freehold, HealthSouth Rehabilitation Services, Ipsen Pharmaceuticals, JKF Rehabilitation Institute, Kessler Rehabilitation Institute, Medtronic, Parkinson's Unity Walk, Swim, Inc, Teva, NJ Chapter APDA and the NJ APDA Information and Referral Center.

### Gift Certificates and Prizes

Ariang Hibachi Steakhouse & Sushi Bar  
Bonefish Grill, East Brunswick  
Carrabba's Italian Grill, East Brunswick  
Cheesecake Factory, Edison  
Chili's Restaurant, North Brunswick  
Denny's, East Brunswick  
Dunkin Dounuts, Somerset  
Home Goods, Hillsborough  
International House of Pancakes, East Brunswick  
Great Clips, Bound Brook  
ShopRite, Bound Brook  
Pathmark, Hillsborough  
Famous Dave's Bar-B-Q, New Brunswick  
UNO Chicago Grill-Metuchen  
Parkinson's Unity Walk  
Perkins Restaurant & Bakery, East Brunswick  
Old Bridge Florist  
Plaza Wine and Liquors, Sayerville  
Red Lobster, East Brunswick  
Stress Factory Comedy Club, New Brunswick  
Stop and Shop, Dayton  
The Ragone and Kortman Families  
Thomas Sweets, New Brunswick  
Spooky Brook Landscaping and Nursery, Somerset  
Heather Wighton & Family

## President's Notes: Benton Yip, NJ APDA Chapter President



Benton Yip, NJ APDA  
Chapter President



### Volunteers Bring Life to and Energy to Service Organizations

The success in any organization, whether it is for profit or non-profit, are the employees (or volunteers) who provide the talent, energy, resources, manpower, and ideas. For the American Parkinson Disease Association, we continue as an entity because of our mission, our focus, our friends with Parkinson's, and our service to the public that gives us the reason for being in existence. Across the United States, we are 57 chapters that are empowered to raise funds for research, increase awareness about Parkinson's, and encourage and support volunteer involvement in the organizations that assist people with Parkinson's. As the number of individuals with Parkinson's continues to grow and the demand for information and services increases, the need for volunteers becomes increasingly important. Community service is an honored American tradition with a deep sense of civic pride in the neighborhoods it serves. At the New Jersey chapter of the APDA, we welcome volunteers to serve in our various committees to provide us the synergy to continue the positive work. Ask us questions. Look into the committees that are now seeking volunteers. Become involved and develop plans to make it go. Down the road, it is your talent and ideas that can make a difference in finding a cure for Parkinson's and help ease the burden.

Sincerely,

*Benton Yip, President  
NJ APDA Chapter*

### Depression and Social Support in Parkinson's Disease (PD)

*A study for PD patients and their families funded by the National Institutes of Health (NIH)*

### Do you have PD and suffer from these symptoms?

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

### HELP US FIND ANSWERS

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

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

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



*Annual People With Parkinson's and Family Symposium  
April 4, 2009  
The Imperia, Somerset, New Jersey*



Barbara Vecchiarelli welcoming conference attendees.



Bill Collier and Vicki Collier staff the NJ American Parkinson Chapter informational table.



Stress? What stress? Attendees enjoy seated chair massage By Healing Touch and Wellness.



Beads by Barbara along with her daughter sell beautiful handmade jewelry. Proceeds go to Parkinson's disease research.



American Red Cross Representative speaking with attendee regarding services available such as Lifeline.



David King, MS, PT speaking with Syd and Roz Helfen.



RWJUH Visiting Nurses at their information booth.

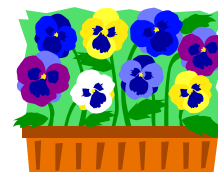


Speaker, David Rintell from Brigham and Women's Hospital meeting conference attendee, Rosanne.



Presenters Sheryl Jedlinski (left) and Jean Burns (middle) with attendee, Nina Bilenkin.

*Annual People With Parkinson's and Family Symposium*  
*April 4, 2009*  
*The Imperia, Somerset, New Jersey*



Dr. Fiona Gupta, Movement Disorder Specialist from Oradell, NJ presenting on The Latest in PD Research and Medical Management.



President Benton Yip reading a proclamation from the Senator Vitale's office stating April as Parkinson's Awareness Month in NJ.



Elizabeth Schaaf, Coordinator with Nikki Tausigg, 2009 Excellence in Service Award Recipient for her dedication and hard work in the Parkinson's community and involvement with the NJ APDA.



Elizabeth with Kevin Kyle, 2009 Excellence in Service Award recipient. Kevin is active in the Engelwood Exercise PD Program and the Haworth Parkinson's Support Group.

**Continued from page 1**

approved and closely monitored protocols. The vector currently used for gene delivery to the human brain is derived from a small virus called adeno-associated virus (AAV), which is not known to cause disease in humans. Three different gene therapies are being tested using this vector. The first FDA-approved experimental gene therapy protocol for PD attempts to silence the subthalamic nucleus (STN), which is a small region in the base of the brain that becomes excessively active in advanced PD with levodopa-associated motor fluctuations. This silencing is accomplished by injecting a gene that makes an enzyme (catalyst) called glutamic acid decarboxylase (GAD), which promotes the generation of an inhibitory brain chemical. Therefore, this approach essentially mimics deep brain stimulation of the STN, which is an FDA-approved surgical treatment for advanced PD. The study was open label with no control group for comparison and included 12 patients with advanced PD at New York Presbyterian Hospital funded by Neurologix. The AAV vector harboring the GAD gene was infused with MRI guidance into one side of the brain. Clinical assessments at one year revealed 27% improvement in motor function on the side of the body that correlated with the treated side of the brain. In contrast, the untreated side showed no significant improvement. Activities of daily living also showed a trend toward improvement. Furthermore, PET scans revealed improved function on the treated side of the brain while the untreated side showed further worsening. Notably, no adverse events related to the surgery or immune reaction to the virus were noted. These encouraging results need to be validated with a more vigorous trial design.

The second approach aims at promoting dopamine production by delivering the gene for an enzyme called aromatic L-amino acid decarboxylase (AADC) which converts levodopa to dopamine. An early phase clinical trial of an AAV vector containing the AADC gene was initiated at the University of California San Francisco and the Lawrence Berkeley National Laboratory in late 2004 and sponsored by Avigen and subsequently Genzyme. The gene is delivered into a part of the brain called the putamen where dopamine neurons project their nerve endings. The expectation is that this manipulation would make putamen neurons respond more readily to levodopa, since AADC gene delivery would enhance dopamine synthesis at the site of its action. The results from PET scans of a few patients obtained 6 months after this treatment reportedly revealed increased activity of AADC in the targeted area of the brain, compared with the patients' pre-treatment scans. Larger controlled trials are needed to determine the efficacy of this gene therapy approach for advanced PD. This strategy is also

being tested in Japan.

The third gene therapy trial that was tested in PD delivered a neurotrophic factor (nutrient molecule for neurons) called Neurturin. Because neurotrophic factors cannot enter the brain when injected into the blood stream, unconventional delivery methods have to be used. For example, a relative of Neurturin called GDNF (glial cell line-derived neurotrophic factor) was tested without gene therapy in PD patients by delivering the protein itself into the fluid space inside the brain as well as into the brain substance. Those earlier trials with GDNF failed and the studies were terminated due to lack of benefit and concerns about safety. Because of difficulties associated with the delivery of proteins into the brain, gene therapy approaches are being developed. Based on encouraging results with AAV vector harboring Neurturin (named CERE-120) in parkinsonian and old monkeys, Ceregene sponsored a small clinical trial in 12 PD patients. A promising safety profile and suggestion of improved parkinsonian motor symptoms led the company, with support from The Michael J. Fox Foundation for Parkinson's Research, to launch a larger multi-center trial of 58 patients. Two-thirds of the participants received a single administration of CERE-120 on both sides of the brain and the rest underwent sham surgery. In November 2008, Ceregene announced that while CERE-120 appeared to be safe and well tolerated, no appreciable difference was detected between the two groups one year after the treatment. Notably, both groups had a substantial number of patients who demonstrated a meaningful clinical improvement from their baseline. This scenario whereby an experimental treatment shows promise in an open label study only to fail in a subsequent controlled, double-blind trial happens too often and underscores the power of the placebo effect.

The next wave of experimental gene therapy for PD will attempt to deliver a normal copy of a gene that is mutated in certain patients with inherited PD. At this point, the best candidate for this approach is the gene called parkin. Mutations in this gene account for about half the cases with young onset PD (before age 40) and because these mutations result in loss of the normal function of parkin. Therefore, replenishing a normal copy of this gene would be expected to correct the deficiency brought about by the mutation. This is in contrast to mutations in two other PD genes, namely alpha-synuclein and LRRK2, where mutations result in gain of a toxic function. In the latter cases, delivering a normal copy of the gene would not help because the abnormal protein would still be present and act in undesirable ways. Therefore, efforts are underway, particularly in Japan where parkin mutations were first identified, to develop viable methods for parkin gene delivery. Initial studies in laboratory animals including monkeys are promising.

**Continued on page 14**



## Commentary on Depression Study

### Matthew Menza, MD

#### Professor, Psychiatry & Neurology, UMDNJ-RWJMS

The March issue of *Neurology* included article highlighting the results from a study that we conducted here at Robert Wood Johnson Medical School.

Some of you were participants in this study. For those of you who did participate, thank you. Your participation has helped us to begin to answer some questions on how to treat depression in individuals with PD. These are long and difficult studies to do, and without your willingness to participate they would not be possible.

So, what can we conclude from the study? First, individuals with depression and Parkinson's disease do respond to antidepressants. This is important because depression in Parkinson's disease is often under-recognized, under-appreciated and under-treated. Commonly, the attitude is, of course you're depressed, you have a serious illness. We have now demonstrated that you should be hopeful that you can feel better with treatment.

Second, the study gives us some guidance on where to start with medications. We found that the medication that affected both serotonin and norepinephrine (nortriptyline) appeared to be superior not only to placebo but also to the medication that affects only serotonin (paroxetine). Paroxetine is a member of a class of drug, the serotonin selective reuptake inhibitors (SSRI) which are widely used to treat depression. Prozac, Lexapro, Paxil, and others are members of this class of drug. Our results suggest that this class may not be as widely effective as the class of drugs which affect serotonin and norepinephrine (dual reuptake inhibitors), a class which includes older antidepressants like nortriptyline (Pamelor) and newer drugs like venlafaxine (Effexor) and duloxetine (Cymbalta). This not to say that the SSRIs won't work in some individuals – many of you are probably on them and they are working – just that percentage-wise, you may be better off starting with a dual action drug.

A third finding which I believe is very important is that nortriptyline was effective for improving a variety of other symptoms which are common in PD and cause significant trouble. Sleep and anxiety, for instance, improved significantly. Also, overall quality of life was much better for those whose depression improved.

The last point which I need to make is that this study, while the largest and most definitive of its kind, is still preliminary. The treatment of depression is always based on an individual's response.

We are not able to predict who will respond to what treatment. Many respond very well to psychotherapies – in fact we have now ongoing a large NIH funded study looking at non-pharmacologic therapies. Often, approaches like exercise and stress reduction are extremely useful.

Regarding medications, many people won't respond to the first medication we try – whether or not it is an SSRI or a dual reuptake inhibitor and we need to serially try medications until we find one that works. Also, many of these medications (including nortriptyline) may have side effects that need to be closely monitored. In the end though, this study helps us decide how to approach depression and reinforces the belief that you should expect to see improvement in depression with treatment.

So, have hope, and thanks to all of you for your participation.



### *Parkinson Disease Clinical Trials*

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

**Go to [www.pdtrials.org](http://www.pdtrials.org)**

### **Still working? Dealing with the stress of commuting?**

Looking to form an informal live "chat" group (to start in the Fall) to meet once a month or so, in Northern Bergen County at a diner or coffee house to discuss adjusting to the "new normal" when you are an active couple, or single person, dealing with PD.

***Please call Elizabeth at (732) 745-7520.  
if you are interested.***



## New Jersey Parkinson's Support Groups

### ATLANTIC COUNTY

**Absecon Presbyterian Church**  
208 New Jersey Avenue, Absecon, NJ 08201  
**Meetings:** Monthly, 1<sup>st</sup> 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, 1<sup>st</sup> & 3<sup>rd</sup> Thursday  
1<sup>st</sup> Thursday: separate caregiver & PWP meetings  
3<sup>rd</sup> Thursday: Guest speaker; no speakers Jul, Aug, Dec  
**Time:** 7:30 p.m.  
**Contact:** Marion Arenas (201) 670-0083

### **Northern Pascack Valley Support Group**

First Congregation Church-Lower Level  
276 Haworth Ave, Haworth, NJ 07641  
No July or August Meetings  
**Meetings:** Monthly, 1<sup>st</sup> 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, 3<sup>rd</sup> 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, 2<sup>nd</sup> Thursday  
**No July or August meetings**  
**Time:** 1:00 p.m.  
**Contact:** Rita Tumas (609) 886-2455

### CUMBERLAND COUNTY

**NO ACTIVE SUPPORT GROUPS**

### ESSEX COUNTY

**North Jersey Support Group**  
Mountainside Hospital (Private Dining Room)  
One Bay Avenue, Montclair, NJ 07042  
**Meetings:** Monthly, 3<sup>rd</sup> 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, 1<sup>st</sup> Wednesday  
No July meeting, No regular October meeting  
**Time:** 7:00 PM  
**Contact:** Diane Gruszewski (609) 254-3096

### HUDSON COUNTY

**NO ACTIVE SUPPORT GROUPS**

### HUNTERDON COUNTY

**Division of Senior Services Office on Aging**  
Route 31, Flemington, NJ 08822  
**Meetings:** Monthly, 4<sup>th</sup> 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, 3<sup>rd</sup> Wednesday  
No Jan, Feb, July, Aug meetings  
**Time:** 1:00 p.m.  
**Contact:** John Wicoff (609) 737-3364

## New Jersey Parkinson's Support Groups



### MIDDLESEX COUNTY

#### ***Evening Parkinson Support Group at RWJUH***

RWJ University Hospital, Auditorium

New Brunswick, NJ 08901

**Meetings:** Monthly, 3<sup>rd</sup> Wednesday (except in Summer-4th Wednesday in July and August)

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

**Contact:** Elizabeth Schaaf (732)745-7520

#### ***Afternoon Parkinson Support Group at RWJUH***

RWJ University Hospital, Auditorium

**Meetings:** Monthly, 3<sup>rd</sup> Thursday (except in Summer-4th Thursday in July and August)

**Time:** 12:30 - 2:00 p.m.

**Contact:** Elizabeth Schaaf (732)745-7520

#### ***Monroe Township Senior Center***

1 Municipal Plaza, Monroe Township, NJ 08818

**Meetings:** Monthly, 1<sup>st</sup> 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, 2<sup>nd</sup> 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, 3<sup>rd</sup> Tuesday

**Time:** 11:15 a.m.

**Contact:** Janet Burns (732) 780-3013

### MORRIS COUNTY

#### ***Care One at Morris***

200 Mazdabrook Road, Parsippany, NJ 07054

**Meetings:** Monthly, 3<sup>rd</sup> Monday

**Time:** 1:00 p.m.

**Contact:** Carol Carlson (973) 714-7652

#### ***Care One at Madison YMCA***

111 Kings Road, Madison, NJ

**Meetings:** Monthly, 2<sup>nd</sup> Tuesday

**Time:** 1:00 p.m.

**Contact:** Carol Carlson (973) 714-7652

#### ***Parkinson's Exercise Program @ Madison YMCA***

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

**Contact:** Betty Peterman (973) 313-2317

### MORRIS COUNTY continued

#### ***Care One at Livingston***

76 Passaic Ave, Livingston, NJ

**Meetings:** Monthly, 1<sup>st</sup> Monday

**Time:** 1:00 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:** Susan or Gabriel-(732) 836-4007

#### ***Parkinson's Support Group Meeting***

Ocean Medical Center Brick Hospital

425 Jack Martin Blvd, Bricktown, NJ 08724

Last Friday of month; call first for details

**Time:** 2:00 pm-3:00 pm

**Contact:** Donna Whitney (732) 836-4614

### SALEM COUNTY NO ACTIVE SUPPORT GROUPS

### SOMERSET COUNTY

#### ***Parkinson's Support Group***

#### ***Fellowship Village (Grill Room)***

8000 Fellowship Road, Basking Ridge, NJ 07920

**Meetings:** Monthly, 3<sup>rd</sup> Tuesdays (No Jul, Aug, Nov, Dec)

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

**Contact:** Maria Santo (908) 580-3836

### UNION COUNTY

#### ***Person with Parkinson's and Family Support Group***

#### ***RWJ University Hospital, Rahway***

865 Stone Street, Rahway, NJ 07065

**Meetings:** Monthly, 2<sup>nd</sup> Wednesday

**Time:** 1:00 p.m.

**Contact:** Debbie Hargiss (908) 272-2362

#### ***Parkinson's and Family Support Group***

#### ***The Presbyterian Church in Westfield***

140 Mountain Avenue, Westfield, NJ 07090

**Meetings:** Monthly, 2<sup>nd</sup> Monday

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

**Contact:** Barbara Ringk (908) 322-9214

### WARREN COUNTY

#### ***Parkinson's Support Group***

#### ***Heath Village***

430 Schooley's Mountain Rd, Hackettstown 07840

**Meetings:** Monthly, 2<sup>nd</sup> Monday

**Time:** 6:30-7:30 p.m.

**Contact:** Jill Mutek, (908) 684-5214/ Valerie Perry (908) 684-5202



## Maximizing Safety When Driving with Parkinson's

By Kay Ballen OTR/L

From the Washington APDA Chapter

Driving requires intact vision, strength, flexibility, coordination, and cognition. Your eyes, muscles, and brain all work together in unison. When driving, your eyes receive information from the environment, your brain processes that information, and tells your muscles when and how to react. Impairment in any of these areas can make driving unsafe.

Vision is the most important thing needed for driving. Approximately 90% of the information you receive from your environment comes from vision. Decisions and reactions are based on what you see. All muscles can be affected by Parkinson's including the eyes. Age related conditions such as glaucoma, macular degeneration, and cataracts affect vision, or the ability to SEE. However Parkinson's doesn't affect the ability to see, but the ability to LOOK, in other words, if affects eye movements. Looking involves rapid eye scanning, which is necessary for good peripheral vision to detect cars and other objects around you so you can navigate where you are going, watch for pedestrians, and read road signs.

The physical symptoms of Parkinson's disease can vary from person to person. Rigidity, tremors, bradykinesia, postural instability, and freezing can all interfere with flexibility, coordination, and execution of movement. Decreased flexibility can make it difficult to get in and out of your car, fasten your seatbelt, or turn your body and head when backing up. Impaired coordination and slower movements can affect how quick you move your foot from the gas pedal to the brake or turn the steering wheel to avoid an accident.

Cognitive changes that occur with normal aging such as memory, attention, processing information, and making decisions can also affect those with Parkinson's. Such changes can slow the brain's ability to process information and make quick decisions. This means slower reaction times. For example, if you see a car pulling out in front of you, your eyes receive the information, but your brain may not think fast enough to tell your muscles to respond and put on the brakes.

Both selective and divided attention is needed for safe driving. Selective attention allows you to select or focus on important information such as responding to changes in traffic and filter out unimportant information. Divided attention allows you to do two things at once like keeping your car in your own lane while reading road signs.

Problems with attention may decrease your ability to handle the demands of driving in heavy traffic or at high speeds. Changes in memory can interfere with obeying traffic rules, remembering where you are going, or operating your vehicle. The inability to make quick appropriate decisions such as when to turn left at an intersection against oncoming traffic or judging when to merge into traffic could put you at risk for having an accident.

With Parkinson's, planning WHEN you drive may be necessary. Some Parkinson's medications can cause daytime sleepiness, decreasing your cognitive and visual reaction times. Some people also experience predictable "wearing off" symptoms prior to taking the next dose of medication which could affect execution of movement.

### THINGS YOU CAN DO

- Drive at the time of day when you are most alert and 'ON'---that is, when you are receiving the most benefit from your Parkinson's medications.

- Exercise good judgment when driving

- Make left hand turns only when there are left arrow signals

- To avoid left hand turns, go to the next intersection and turn right, then make 2 more right turns at the next 2 intersections.

- Plan your route before you get in your car

- Only drive in familiar places

- Avoid rush hour or heavy traffic to reduce anxiety

- See an eye care specialist at least 1x/year or if you experience changes in your vision

- Keep your windshield clean and make sure your wipers and headlights are working

- AARP classes are available to refresh your driving safety skills; some insurance companies will then reduce your insurance rates!!

- Stay active with regular physical exercise including walking, stretching, and strengthening

- Exercise your mind daily with crossword puzzles, trivia, computer or board games

To further assess your safety, Occupational therapy can complete a clinical driving evaluation at the Booth Gardner Parkinson's Care Center in Kirkland, WA. This test is done in the clinic to assess visual processing and reaction times, physical strength, flexibility, and functional cognitive skills needed for safe driving. It identifies safety concerns, the need

**Continued on page 11**



### Continued from page 10

for further visual or cognitive testing, and recommendations, if needed, for an on road assessment. Resources for alternative types of transportation are provided for those who are considering retiring from driving.

In conclusion, refresh your knowledge of safe driving, adjust your driving habits, listen to those who are concerned with your driving, begin planning ahead for alternative ways to stay independent in the community and most important IF IN DOUBT follow up with your physician.



### *Scenes from the Unity Walk Bus Group*

*April 25, 2009  
NY Central Park*



### CARE FOR THE CAREGIVER SUPPORT GROUP



This encouraging support group is open to community members who are caregivers to family and/or friends as well as former caregivers. This group is for caregivers of one with a chronic illness. The group supports caregivers to share experiences, coping strategies and resources with those in need of support.

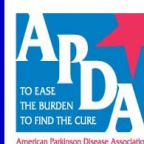
Meetings will be held first Tuesday of each month.

TIME: 7:00PM -8:30PM

RWJ Rahway Fitness & Wellness Center  
2120 Lambert's Mill Road  
Scotch Plains, New Jersey

There are no fees and pre-registration is not required. All interested parties are welcome to walk-in and join this confidential and caring support group.

Please kindly call for inquires or concerns:  
732-499-6193



*The APDA National Young Onset  
Center's newly re-designed  
Website is now online!*

*Visit us at [www.youngparkinsons.org](http://www.youngparkinsons.org)*

On our new site you will find:

- **All new content**

Articles & information about education, health/wellness, support, advocacy, and more.

- **Faces of Experience**

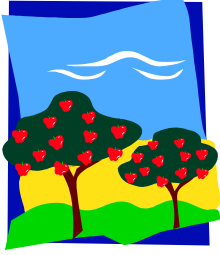
People with YOPD share their stories of challenge and triumph.

- **Calendar of Events**

Includes details about PD events by state that may be of interest to you.

- **Publication Ordering/Downloading**

Our new registration system allows you to quickly and easily obtain APDA publications.



## Upcoming Educational Events and Support Group Meetings Summer/Fall 2009

### **RWJUH Parkinson's Support Group Meetings**

#### **Evening Parkinson's Support Group**

Location: RWJUH, New Brunswick

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

Hospital Auditorium (*unless otherwise noted*)

#### **Wednesday, June 17, 2009**

Topic: Social Security Disability SSDI and SSI Benefits

Speaker: Kevin Liebkeman, Esq.

Legal Services of New Jersey, Inc.

#### **Wednesday, July 29, 2009 (Please note different date)**

Open Discussion Meeting

#### **Wednesday, August 26, 2009 (Please note different date)**

Showing Video: The Incurable Optimist,  
Michael J. Fox and Discussion Meeting

#### **Wednesday, September 16, 2009**

Topic: Coping with Challenges and PD

Speaker: Jackie Christini, APN

JFK Neuroscience Center

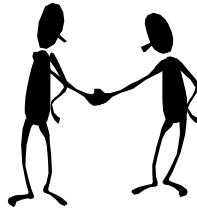
#### **Afternoon Parkinson's Support Group**

Location: RWJUH, New Brunswick  
12:30 p.m. to 2:00 p.m. Hospital Audi-  
torium (*Unless otherwise noted*)

#### **Thursday, June 18, 2009**

Topic: Physical Rehabilitation and PD

Speaker: Dr. Paul Abend, RWJUH



#### **Thursday, July 30, 2009 (please note different date)**

Open Discussion Meeting

#### **Thursday, August 27, 2009 (please note different date and different time for this luncheon)**

#### **Summer Luncheon**

*(ALL PD groups are invited to attend!)*

Houlihan's Restaurant, North Brunswick, NJ  
20.00 Per Person. Please RSVP by August 20.  
11:30 AM

#### **Thursday, September 17, 2009**

Topic: From Physical Therapy and Community

Speaker: David King, MS, PT

Kessler Rehabilitation Institute

### **Living Well With Parkinson Disease Fall Symposiums**



#### **Fall North Jersey Parkinson's Symposium**

Speakers: Dr. William Severt and Dr. Matthew Menza

Saturday, October 10, 2009 Teaneck Marriott

10:45 a.m. to 3:00 p.m.

*More details to follow*

#### **Fall South Jersey Parkinson's Symposium**

Saturday, November 14, 2009

Speakers: Dr. Amy Colcher and Barry Jacobs, PhD.

The Mansion, Voorhees, New Jersey

10:45 a.m. to 3:00 p.m.

*More details to follow.*

### **Sculpting with Parkinson's for Peace of Mind**

#### **Learn How to Sculpt!**

**Two Day Class: \$35.00 (Per Person)**

**For People with Parkinson's  
and their Families**

**Friday, October 30 and Friday, November 6,**

**1:00 PM to 3:00 PM**



The creative process is enjoyable and can help increase focus, patience, distraction from pain, anxiety and depression, in a nurturing environment. Participants feel comfortable, enjoy the socialization, take their mind off PD and don't feel frustrated by what they can't do. Register today by calling (732) 745-7520. No prior experience needed! Be prepared to have fun!

**NEW!**

**University Without Walls and  
Caregiver Connections present:  
New Telephone Series:  
Caring For a Loved One with PD  
This group is for the Caregiver, Friends and  
Family Members of People with PD**

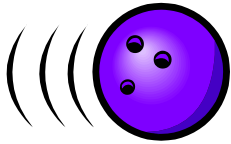


**Facilitator: Elizabeth Schaaf**

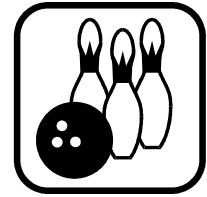
**Monday Evenings: 7:30 p.m. to 8:20 p.m.**

**Dates: November 2, 9, 16, 23 and 30. Topic details to follow.**

Registration fee is \$10 and \$15 for each series. Scholarships are available. To register, or for more information, call Caregivers' Connections toll-free (877) 819-9147, or Fran Rod, NJ Outreach Coordinator, at (973) 763-1511.



***Strike Out Parkinson's Bowl-a-thon!***  
***March 22, 2009-Brunswick Zone-***  
***Carolier Lanes-North Brunswick, NJ***



***A Special Thank –You To Our Generous Donors***

***Applebee's of Hillsborough***

***Build A Bear Workshop***

***Brunswick Zone-Carolier Lanes, North Brunswick***

***Famous Dave's Barbeque, Hillsborough***

***Ferraro's Italian Restaurant***

***Golfsmith, Bridgewater***

***Houlihan's, New Brunswick***

***Jersey Paper Company, Edison***

***Judy Kides***

***Kathy Cevera***

***Kohl's, Hillsborough***

***Lowe's, Hillsborough***

***Magic 98.3***

***Mary Cook***

***Millers Party Rentals***

***McDonald's, South Brunswick***

***Mi Amore Restaurant***

***New Brunswick State Theater***

***New Jersey Devils***

***New Jersey Giants***

***Olive Garden, East Brunswick***

***PDTalks, Inc.***

***Ruby Tuesday, Somerset***

***The Stress Factory, New Brunswick***

***Saladworks, New Brunswick***

***ShopRite, Somerset***

***Super Stop n' Shop, Somerset***

***Target, Bridgewater***

***The Bagel Peddler, Somerset***

***Venus Jeweler's, Somerset***

***The Ragone and Kortman families***



***Arely Sequeira, Captain (far right) with her team, The Pin Shakers! They had the top raising team and individual!***



***The Moskowitz Family Bowling Team***



***Spare Me! Team-Kathe Johnson (Right) Team Captain and Assistant Coordinator with team-mates.***



## Join the 23andMe Parkinson's Community

23andMe, the leading provider of personal genetics services, has launched a revolutionary web-based research initiative to discover new ways in which our genes and environment influence Parkinson's disease.

The members of the 23andMe Parkinson's community – already more than 2,000 strong – are helping advance our collective understanding of Parkinson's disease while at the same time gaining unprecedented information about their own DNA and how it may affect their health.

Historically it has been a challenge for scientists to assemble and study populations of more than a few thousand individuals. 23andMe strives to assemble a much larger and diverse patient population – at least 10,000 individuals – that is available for ongoing research purposes. A large population is critical for magnifying the data contributed by each individual into a clear and readable signal that will allow scientists to push PD genetics closer to practical therapeutic relevance in treating the disease, as well as in helping to find a cure.

The NJ APDA chapter recently joined 23andMe in making this Personal Genome Service™ available to NJ Parkinson's patients for \$25 instead of the usual \$399 price, thanks to a grant from Google co-founder Sergey Brin. The requirements are simple: provide a small saliva sample for genetic analysis and agree to participate in online surveys about your experience with Parkinson's.

If you are interested in learning more about the 23andMe program, please visit [www.23andme.com/pd](http://www.23andme.com/pd). If you would like to obtain a discount code for the \$25 offer, please contact Elizabeth Schaaf, NJ APDA I&R coordinator at 732 745-7520 or email [Elizabeth.Schaaf@rwjuh.edu](mailto:Elizabeth.Schaaf@rwjuh.edu).

### Continued from page 6

Despite encouraging safety data from the early clinical trials to date, vigilance for possible adverse effects as a result of long-term production of the delivered genes as well as the viral vector itself is paramount. Potential adverse consequences that need to be watched for include immune reaction, tumor formation, and diffusion of the vector away from the intended site. For these reasons, gene therapy remains in the experimental realm in 2009.

## BRAIN & MIND FITNESS TRAINING

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

### RUTGERS UNIVERSITY

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

The class is offered as part of research, there is no cost to you.

Class meets for five 90-minute sessions and five 2-hour sessions at your convenience, and is taught by advanced graduate students in psychology.  
No medications involved.

**Taking more participants this fall!**

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



**Donations may be sent to:**

**NJ APDA Chapter  
120 Albany Street,  
Suite 360**

**New Brunswick NJ 08901**

*Donations help support  
local education programs and  
Parkinson's research.*

*We greatly appreciate your support!*

## 15th Annual Parkinson's Action Network Forum

By Vicki Collier, Treasurer, NJ APDA

On March 15-17, 2009, nearly 300 members of the Parkinson's disease community from across the country gathered in Washington DC for the Parkinson's Action Network's (PAN) 15<sup>th</sup> Annual Research & Public Policy Forum, which included two days of training leading to a final day of meetings with Members of Congress on Capitol Hill.

During the Forum, attendees learned about PAN's 2009 legislative agenda, the issues important to the Parkinson's community, the latest scientific advances in Parkinson's disease research, and they experienced first-hand, the power of advocacy. This gathering of PAN advocates and leaders in the Parkinson's community provides the essential infrastructure for connecting and engaging new PAN supporters with those who are active in grassroots advocacy work year-round.

Meetings were arranged in the offices of Senators Lautenberg and Menendez, as well as Representatives Pascrell, Holt, Pallone, and Lance, to request that they take action on initiatives important to the Parkinson's community. This year, PAN specifically asked them to join the Bicameral Congressional Caucus on Parkinson's disease; support the Department of Defense Neurotoxin Exposure Treatment Parkinson's Research (NETPR) program; and co-sponsor the National MS and Parkinson's disease Registries Act. The current lack of core knowledge about who has Parkinson's disease and why inhibits research, programs, treatment, and services. A national registry of accurate incidence and prevalence information is critical to gain a better understanding of this disease which is estimated to affect more than 1.4 million Americans.

The three-day event was a unique opportunity for members of the Parkinson's disease community to be a part of the unified voice of those affected by this progressive and debilitating neurological disease. Those interested in joining the fight to improve treatment and ultimately find a cure for Parkinson's disease are encouraged to visit PAN's website at [www.parkinsonsaction.org](http://www.parkinsonsaction.org).



**You are Invited To:**

**Luncheon and Get Together**

**At the Home of Bill Lear (Former NJ APDA  
President) and Cathy Lear**

**Saturday, June 27, 2009- Burlington, NY**

**RSVP by 908-967-3906 (Cathy's cell) by June 20.**

## Are You Interesting In Volunteering

We currently have openings on the  
following committees:

**Advocacy & Public Awareness**

**Event Planning & Fundraising**

**Membership**

**Publicity**

If you would like to learn more about these opportunities, or are currently available to volunteer, please contact us at [njapda@yahoo.com](mailto:njapda@yahoo.com) or by phone: 908 303 0090. Additional information is also available at our website: [www.njapda.org/volunteer](http://www.njapda.org/volunteer).



### 15th Annual Parkinson's Action Network Forum-March 2009

(From left to right)

Angela Imhof, Joe Narciso, Charlene Narciso, Representative Bill Pascrell Jr., Vicki Collier, and Benton Yip.



**NJ APDA Parkinson I & R Center**  
 120 Albany Street, Suite 360  
 New Brunswick, NJ 08901  
[www.njapda.org](http://www.njapda.org)



Phone: 732-745-7520  
 Fax: 732-745-3114  
 Email: [Elizabeth.schaaf@rwjuh.edu](mailto:Elizabeth.schaaf@rwjuh.edu)

*New Jersey American 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, CHES**  
 Coordinator & Editor  
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 Coordinator, Community Education  
 Robert Wood Johnson University Hospital  
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**Kathleen Johnson**  
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**Benton Yip**  
 President, APDA New Jersey Chapter  
[Njadpa@gmail.com](mailto:Njadpa@gmail.com)  
 (732) 632-1737  
 For Donations::  
 NJ APDA Chapter  
 120 Albany Street,  
 Suite 360  
 New Brunswick NJ  
 08901



**American Parkinson Disease  
 Association  
 National Office**  
 135 Parkinson Avenue  
 Staten Island, NY 10305  
 Phone: 1-800-223-2732  
[www.apdaparkinson.org](http://www.apdaparkinson.org)

 **Painting with Parkinson's for Peace of Mind-Spring Series**  
*Painters displaying art work at a recent  
 Painting with Parkinson's art class series, lead by artists,  
 Sandy Frank and Elena Tuero.*

 **Moving? Or Have You Moved?**  
**Address/Name Correction Form**  
**PD Newsletter**

**NJ APDA Parkinson's Disease  
 Information and Referral Center**  
**120 Albany Street, Suite 360**  
**New Brunswick, NJ 08901**

Name (s) \_\_\_\_\_

New Address \_\_\_\_\_

Old Address \_\_\_\_\_

New Phone \_\_\_\_\_

Email \_\_\_\_\_

Comments \_\_\_\_\_