



Parkinson's

Companion

Voices of Parkinson's Our Traveling Companions by Gay Palazzo

Of all the companions I might want to take along with me on a trip, traveling "with PD" is not one that I would choose. However, it goes with me, like it or not. Parkinson's disease has been my constant companion for the last three years. During this time I have been on many trips that I might have otherwise put off. With a little effort, it has been possible to sometimes forget about this traveling partner!

I read in a book about Parkinson's that if you like to travel, there is no reason to put it off (in other words, go while the going is good!). I took that advice to heart and spent weeks in libraries and book stores perusing the shelves. I then spent late evenings on the internet where I consulted

vacationstogo.com, tripadvisor.com, and many other websites that took me to some places I have been to and many that I have not. My "travels" took me around New England, the US, and the world. I will never take most of these trips, but I sure enjoy planning them. I did not ever consider my health status because I can do anything when it is in my mind. I never had to limit my dreams.

As it turned out, I did have the opportunity to travel to the US state that is the farthest away from New England. Can you imagine a better place to be in January than Oahu and Hawaii! My husband is an environmental scientist and was doing research at the military bases in Hawaii. I was able to accompany him. Before leaving on any trip,

there are many things to get done. With PD, careful preparation is key and all the pre-trip work pays off. There are many books about PD that give you lots of travel advice. I won't repeat the advice here but I do have a few hints that may be helpful. The first involves medications. As you already know, determining a medication schedule is difficult on a trip but imagine when your airline travel is 14 hours long! Some meds make you tired, some keep you awake, some you have to take with food and others on an empty stomach. If you need anti-nausea medicine, be sure that it is compatible with



Gay Palazzo recently retired from her position as Resource Coordinator for Casey Family Services in White River Junction, VT. She loves traveling, volunteering, writing, and spending time with her eight grandchildren. She was an editor for the *Journal of Neurosurgery* and the book division of the American Association of Neurological Surgeons. Gay and her husband Tony reside in Lebanon, NH.

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A Note from the Coordinator **Diane L. Church, PhD**

I hope that you are all indulging in fresh local produce, enjoying time at home, traveling, and finding other ways to "beat the heat." Autumn is right around the corner, and we are looking forward

NH on September 15; our Fall Educational Symposium in Bedford, NH on October 13; and the New England Regional Biennial Parkinson's Conference on November 4-5 in Sturbridge, MA.

We are still looking for leaders for proposed support groups in Plymouth and Meredith. If you are able to take on this rewarding volunteer job, or can locate someone in these towns to assist the Parkinson's community in this way, please let me know!

to three great events: APDA NH Chapter's "Walk-in-the-Park" fundraiser for APDA Parkinson's research programs in Nashua,

BEAT THE FREEZE IN PARKINSON'S DISEASE

“When I ‘freeze,’ I feel like my feet are glued to the ground! It’s frustrating and scary, especially if I am in a crowded place or crossing a parking lot or road. And sometimes my words and thoughts get frozen, too.”

- Adrienne, 72, person with Parkinson’s

About one third of people with Parkinson’s disease experience freezing episodes. Freezing episodes are sudden, short, transient blocks of movement that occur primarily with initiating walking, turning, navigating through narrow spaces or approaching obstacles. Freezing can last just a few seconds or up to several minutes. Freezing can limit household and community mobility, increase risk of falling and contributes to reduced socialization and quality of life.

Ten Tips to Put the Freeze on Freezing!

- 1) Try another movement** – raise an arm, touch your head, point to the ceiling; then re-start
- 2) Change direction:** if you can’t move forward, try stepping sideways and then go forward
- 3) Carry a laser pointer in your pocket;** when you freeze – shine the laser in front of your foot and step on the light – this cue can help you re-start
- 4) Visualize an object** on the ground in front of you and try to step over it
- 5) Wear a metronome on your belt or carry a small one in your pocket** – turn it on and the external beat can help you re-start
- 6) Try humming a song** and time your re-start with the beat of the music
- 7) Count “1-2-3-go”** and then step forward
- 8) Shift weight side to side** to help initiate taking a step
- 9) March in place a few times** and then step forward
- 10) Don’t fight the freeze by trying harder to step forward** – shift your attention from moving the legs to moving the arms – then resume walking forward

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www.bu.edu/neurorehab/resource-center/
Toll Free Exercise Hotline (to speak with a physical therapist): (888) 606-1688
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your PD meds. Don’t forget to bring an empty bottle for water that you can fill once you have passed security.

My PD is often not noticeable by others. This is a good thing since I like to be as “normal” as possible, but it is also a bad thing since sometimes my behavior just isn’t normal and those around me don’t know why. I tend to trip when hiking on uneven terrain and I am very afraid of falling in a place where I can’t be easily helped. On my recent trip, I sometimes found that it was just too much effort to go sightseeing. I found myself saying “I am fine, just need a little time, you go ahead.” By staying behind, I saw and did things that I would otherwise have missed. For example, I took an Aqua Hula dancing class offered at the hotel

where we stayed. Another day I spent the afternoon in the park watching Tai Chi classes.

My next travel tip may surprise you. To make your trip more comfortable and less stressful, invest in a fancy cell phone! You will be surprised at some of the features that it has. You can use it as a camera to take pictures, and you won’t have to carry a large case around. You can then send that picture to your family back home (like a postcard). There are all kinds of apps for traveling including an app that you can use to get driving directions. You can make dinner reservations using the “Open Table” app. There are apps to guide you on walking tours. Your phone automatically gives you the correct time and weather for the place you are visiting. You can use the internet to connect

with your newspaper back home to see if you are missing anything (most likely you aren’t). The app “Places” can help you locate such necessities as an ATM machine, a coffee shop, and the hours that a museum is open. And oh yes, you can use your phone to make calls as well, saving you time and effort. With a simple call, you can arrange a meeting place that will allow you a little time to rest. For me, a phone meant that I could locate my husband when we had a mix-up on where to meet! That cell phone may be your new best friend.

Another new “gadget” is a tablet/iPad, which can be a wonderful aid on a trip. I like the 7-inch Kindle Fire because it fits in my purse. This means that I don’t need to carry a suitcase of books to read and I can also listen to a book being

read using headphones. I can get wi-fi in most hotel lobbies and other public places, and I can journal my trip if I want. During those long waits at airports, I can play my favorite word games to keep me occupied. And if anyone wants to see a picture of my grandchildren, I have one at my fingertips...

So, I encourage you to follow the advice given in every PD book. Research where you are going. Talk to others with PD and find out what works best for them. Learn ways to make the most of your trip, plan time for relaxation as well as touring, take lots of pictures, and store lots of memories. My husband and I will never forget our final evening in Hawaii when we ate outside on a lanai and watched the sun as it set over the Pacific Ocean.

SYMPOSIUM SUMMARY: Challenging the Changes

Dartmouth-Hitchcock Medical Center, Lebanon, NH
March 10, 2012

This educational event was dedicated to the memory of Francis "Punky" Henry.

1 Diane L. Church (left), Coordinator of the APDA Parkinson's Center at DHMC, and Maureen Chamberlain, President of the APDA NH Chapter, provided introductory remarks.

2 Dawna Pidgeon, PT (right) answered Sylvia Morton's questions after her presentation, "Physical Therapy Intervention for Improved Mobility & Function." Ms. Pidgeon discussed how a physical therapy assessment and intervention can help manage symptoms related to Parkinson's disease and improve quality of life, defined current best practice recommendations for physical therapy intervention, and discussed effective strategies to improve mobility, strength, and flexibility and to decrease fall risk. Ms. Pidgeon is a physical therapist in DHMC's Department of Rehabilitation Medicine. She specializes in screening and treating those with balance disorders, coordinates the Balance & Vestibular Program, chairs the Falls Risk Reduction Interdisciplinary Task Force, and leads the Parkinson's Wellness Program. She is actively involved in numerous research projects and balance/falls programs throughout New England.

3 Kesstan Blandin, PhD received assistance from Ray Kulig, DHMC Videoconference Services Manager, prior to her presentation, "Changing Identities: Living with Neurodegenerative Disease." Dr. Blandin discussed the changes that one experiences when living with a chronic condition such as Parkinson's disease, focusing on self and identity, loss and grief, and meaning and "generativity." "Investing one's wisdom and substance in forms of life and work that outlive the self and guide the next generation." Dr. Blandin is a psychologist, researcher and writer who, through her work with the Alzheimer's Association of MA/NH and the Dartmouth Centers for Health and Aging, provides education and counseling to families, including those with Parkinson's, who are dealing with cognitive decline and dementia. She also provides professional training programs for staff, clinicians and therapists, and those working with the developmentally disabled. She is currently writing a book about grief and loss of self in dementia.

4 Kate Gamble, BFA, PT (left) and Annie Mailloux, social worker and dancer, led enthusiastic participants in a Dancing with Parkinson's Workshop inspired by the Mark Morris Dance Company's Dance for PD®. Participants engaged their minds and bodies as they moved creatively to music, were guided through dance segments designed to help find one's own internal graceful movement and response to music, and experienced how dance enhances flexibility, coordination and confidence. Ms. Gamble has taught dance and choreographed for over 20 years. She is the past Artistic Director of the Braided Light Dance Company (Jacksonville, FL), trained with the Mark Morris Dance Company, and brought "Dancing with Parkinson's" classes to Lebanon, NH.

5 Participants reported that they were delighted with the Dancing with Parkinson's Workshop!





When the Parkinson Patient Needs Surgery

Michael Rezak, M.D., Ph.D., Director, Movement Disorders Center, Neurosciences Center, Central DuPage Hospital, Winfield, IL

Recently, I have received a number of inquiries regarding PD patients who have scheduled surgical procedures and some who have required emergency surgery. Special consideration must be given to the PD patient that requires any type of surgical intervention. The physical and emotional stress that surgical procedures can impose impacts PD management. Foreknowledge of potential problems may preclude their development.

In the following paragraphs, I have chosen a question and answer format using actual questions posed by patients and their families, as well as by physicians. The selected questions will also address potential complications seen in PD patients that undergo any surgical procedure.

Q. When should PD medications be discontinued before surgery, and how soon can they be restarted after surgery?

A. PD medications should be continued as close to the surgical procedure as possible. This is typically about three hours before the procedure, allowing the patient to remain as comfortable as possible. There is no longer a need to discontinue MAO-B inhibitors (particularly Azilect®) before surgery as this class of medicine has been shown to be safe with anesthetics and most pain medicines. The only contraindicated pain medicines are meperidine and tramadol. To date, there have been no negative interactions documented with MAO-B inhibitors and pain medicines. Following surgery, PD medications should be restarted as

soon as the patient can safely swallow. Unfortunately, there are very limited number of effective dopaminergic drugs that can be administered by routes other than orally. The exceptions to this are Apokyn®, Cogentin®, and Zelapar®. Apokyn® is an injectable dopamine agonist and is the most efficacious of the previously mentioned drugs, but must be used with caution in the post-operative period (especially if an effective dose has not been established pre-operatively) and only if an anti-emetic is used concurrently. In most cases, if a patient is recovering from gastrointestinal surgery that requires l-dopa, I recommend giving medications via nasogastric tube with suction off and the tube clamped for 30-45 minutes after the medicine is delivered to allow for absorption. In this type of situation, Apokyn® could also be used here, either as the primary medication or as an adjunct. Zelapar® is an MAO-B inhibitor that is uniquely absorbed through the oral mucosa thereby bypassing the gastrointestinal track.

Q. What are the dangers in delaying restarting dopaminergic medications after surgery?

A. The post-operative period can be difficult under any circumstances; however, with the additional burden that PD imposes, resumption of optimal motor function as soon as possible is of paramount importance in order to minimize any of the potential problems.

First, delay in reinitiating PD medications can compromise motor function including those of respiratory (breathing) and pharyngeal (swallowing) muscles. Poor respiratory muscle function can lead to impaired coughing and restricted movement of the respiratory muscles (limiting deep breaths). Additionally, swallowing problems can develop or worsen without PD meds, thus increasing the risk of aspiration. These problems, taken together with the decreased ability to move about, make the common post-operative complication of pneumonia much more likely.

Second, the rigidity, bradykinesia, and

resultant decrease in movement brought about by the lack of PD medications increase the post-operative risk of developing blood clots in the legs (deep venous thrombosis (DVT)) related to sluggish blood flow. In some cases, these blood clots can travel to the lungs causing a life threatening pulmonary embolus. Mobilization is therefore a major post-operative goal after any surgery and not being on PD medications increases risks and delays optimal rehabilitation.

Finally, a rare, but potentially life threatening condition known as neuroleptic malignant syndrome (NMS) must be a concern whenever dopaminergic drugs are stopped abruptly. In NMS, mental status changes, rigidity, tremor, fever, and autonomic instability can have serious consequences. If recognized early, treatment can be lifesaving.

Q. Should a PD patient do anything special pre-operatively to maximize the possibility of a good recovery?

A. Of course, obtaining general medical clearance prior to surgery is the standard of care. This allows for correction of any problems before the surgical procedure. Additionally, I recommend that some patients undergo a formal video fluoroscopic swallowing evaluation, as well as obtain pulmonary function tests so that baseline measurements can be obtained and appropriate planning for potential post-operative difficulties be instituted. Also, it is important to stop any prescription or over-the-counter medications that increase bleeding such as Coumadin®, Plavix®, aspirin, vitamin E, Gingko Biloba, etc. Maintaining good hydration and appropriate nutritional status, as well as optimizing overall physical conditioning, will maximize the potential for a good and smooth recovery.

Q. What medications should be avoided following surgery?

A. Needless to say, all drugs that block dopaminergic transmission need to be avoided. Post-operative nausea and vomiting are extremely common, and medications such as

Reglan®, Compazine®, and Phenergan® are considered first-line medications to treat this problem. Because of their interference with dopamine transmission, they will certainly worsen PD symptoms and should therefore be avoided. If treatment for nausea and vomiting is needed for the PD patient, the drug of choice is Zofran® or alternatively Tigan®. These drugs do not interfere with dopamine function and can be given intravenously or orally.

Post-operative confusion and agitation are another situation where dopamine-blocking agents are often employed. The older neuroleptics such as Haldol® and closely-related drugs should be avoided. The newer, so-called, “atypical neuroleptics” such as Abilify®, Risperdal® and Zyprexa® may also have a deleterious effect on motor function in PD patients. The drugs of choice for the treatment of post-operative delirium are Seroquel® and Clozaril®. They are effective and have minor impact on PD symptoms. Seroquel® is easy to use and is considered the best option for the PD patient.

In general, when the PD patient needs hospitalization, multiple copies of the medication schedule with exact times of administration should be supplied to all of the physicians and nurses involved in their care. Upon arrival at the hospital, a discussion of PD and the importance of proper medication administration should take place with the staff. If possible, an advocate (e.g., spouse, child, caregiver) should be assigned with the task of assuring that medications are given on time and in the correct doses.

In closing, I hope that through these questions and answers I have emphasized that “micro-managing” the PD patient before, during, and after a surgical procedure decreases the risk of complications and increases the likelihood of a good and full recovery. As always, it is important for the PD patient to be his or her advocate in assuring that all of the details are in order.

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MEDICAL ALERT SYSTEMS

May be Your Lifeline:

Keeping you safe, enabling independence, and providing your loved ones peace of mind. **But which system is right for you?**

There are several review sites about Medical Alert Systems (if you don't have a computer, please ask your local librarian for help in accessing and printing these reviews):

- www.medicalalarmstoday.com/aarp-medical-alarms-reviews.html
- <http://medical-alert-systems-review.toptenreviews.com>
- www.happyhealth.net/medical-alert-reviews

Features identified as important by our Parkinson's community:

Contract: Having a contract that will let you cancel if your situation changes

Range: Consider your activities: "My mom's system covered as far as the back yard, so she could still garden."

Testing: Some systems phone once a month to test the system

Who the system will contact in an emergency: 911 or a friend/family member?

Contacting 911 might provide the most direct medical response. But if you have a DNR ("Do Not Resuscitate") order, remember that Emergency Medical Technicians are trained to do everything possible, including resuscitation, to get a live person to the emergency room.

From an Emergency Medical Technician:

Make sure that the 911 system can find you in case of an emergency, whether you are using your telephone or a Medical Alert System to report a problem. Call your local phone provider to verify your address as it is entered into the 911 system based on your landline phone number. Check that the Medical Alert System you are considering will be answered locally so that 911 emergency responders will be on their way to your address quickly.

Check with your local hospital for possible discounts on Medical Alert Systems.

For example, Lifeline® has an excellent program based at Dartmouth-Hitchcock Medical Center but available to all, regardless of whether you receive medical care at DHMC:

"Dartmouth-Hitchcock is proud to offer:

The Philips Lifeline® Personal Response Service. Our program is a volunteer supported service and is designed to give personalized service to meet the needs of individuals and their families in our communities. This helps to keep the cost as low as possible. If cost is an issue, we have sliding-fee and full scholarship programs available for qualifying subscribers. Our goal is to provide affordable Lifeline® service to all. Subscribers may use the physician and hospital of their choice."

For more information contact:

Dartmouth-Hitchcock Lifeline® Program
patients.dartmouth-hitchcock.org/lifeline.html
(603) 653-1610
(888) 699-4034 (toll-free)

What our Parkinson's community likes about the following Medical Alert Systems:

Lifeline® from Phillips:

- ✓ Lifeline® responders who answered calls were described as excellent, caring and concerned, effective and personable.
- ✓ Lifeline® can be moved from place to place, even for use in another state
- ✓ Fast response time

From the owner of a Home Health Care agency:

- ✓ Customer service: fast resolution of any technical issues, fast installation time, local technicians, discounts often available
- ✓ Auto-alert feature, which senses if the person wearing the unit has fallen. If the person does not answer a check-in call, help will be dispatched automatically.



Jitterbug Plus® phone from Samsung:

- ✓ Relatively inexpensive
- ✓ Easy to use: Can be hung on a lanyard for portability, and the buttons are large so it is easy to press "9-1-1".
- ✓ Health and medical "apps" can be added at additional monthly cost:
 - "5Star Urgent Response" transforms the phone into a personal safety device. Press 5 and then * to speak immediately with an agent who will quickly identify your location, evaluate your situation and get you the help that you need.
 - "LiveNurse" provides unlimited access to health advice from experienced, registered nurses, 24/7.
 - "Medication Reminders" is a service that calls you daily to remind you to take your medications at the correct time of day and when to refill your prescription.

911 Guardian Alert® by Logic Mark:

- ✓ Relatively inexpensive. An extra alert button for a family caregiver can be added at no additional charge.
- ✓ The system is portable and nationwide. Just call the company with an updated phone number and address when you travel.
- ✓ Ease of use: Direct connection to 911 with the push of a button. The speaker is in the button pendant so you don't have to be close to a telephone or base to communicate. Loud enough for the hearing impaired to hear and talk with the 911 responder.
- ✓ Broad range: "It has worked in the barn, basement, yard, and inside our entire house."

Driving Safely with Parkinson's Disease

Peggy P. Barco, MS, BSW, OTR/L, Driving Rehabilitation Specialist, Program in Occupational Therapy, Washington University Medical Center in St. Louis, and David Carr, MD, Professor of Medicine and Neurology and Clinical Director for the Division of Geriatrics and Nutritional Science, Washington University Medical Center in St. Louis, Medical Director of the Rehabilitation Institute of St. Louis



DRIVING IS ONE OF those important activities that provide independence and the ability to stay connected within the community. But driving is also a public-safety issue – especially when one has a medical condition like Parkinson's.

PD is commonly known as a disease that affects movement and motor function. But there can also be vision, cognitive, and perceptual changes – especially as the disease progresses. Being aware of the changes that can occur with Parkinson's, how these changes can impact driving safety, and using good judgment regarding one's own driving ability are important in determining who is fit behind the wheel.

The following non-motor PD symptoms have the potential to greatly decrease driving safety in the following ways:

1) Decreased contrast sensitivity affects the ability of an individual to detect objects in low contrast environments – such as pedestrians in crosswalks at dusk or on a foggy day. A recent study of drivers in low contrast light conditions confirmed that those with PD displayed less control over their vehicles, had slower responses to hazards, and committed more safety errors than those without PD.

2) Decreased proprioception occurs with PD and in aging, resulting in a reduced sense of spatial orientation. Inability to sense the relative positions of one's arms and legs in space leads to clumsiness and falls as well as difficulties in coordinating movements. Although the specific risks of decreased proprioception

for Parkinson's drivers have not been studied, an example might be difficulty with positioning one's foot correctly on the gas or brake pedal.

3) Difficulties with cognitive functioning as PD progresses include decreases in attention, memory, problem solving, planning, visual-spatial abilities, and decision making. Studies indicate that individuals with PD, and especially those with cognitive changes, are less safe drivers.

While many persons with PD (especially those in the early stages) remain safe drivers, it is very important to be aware of the cognitive and perceptual changes that can occur as the disease progresses and to adapt one's driving accordingly. Appropriate changes in one's driving habits might include driving only during daylight and avoiding venturing out on foggy days, driving only in familiar areas, and driving only at times when fewer cars are on the road and in areas with lower traffic density.

The Driving Assessment Process

Often families and individuals have difficulty assessing driving safety objectively. Indications of driving difficulties can include a recent history of accidents/tickets, difficulties maintaining good lane positioning, delayed responses to traffic lights or planning lane changes, difficulty deciding when it is safe to make a turn, relying on non-drivers in the car

to help with decision-making, and getting lost while driving.

If you, your family member, or physician are concerned about your driving safety, it is advisable to seek a driving assessment, which is provided by an occupational therapist who is also a driving specialist. These assessments usually take a few hours and include in-depth clinical testing of vision, sensory, motor, and cognitive functions. In addition, the assessments involve an on-road driving assessment to judge how well an individual's driving ability is in real traffic conditions. These on-road assessments are done in a driving evaluation car (with a passenger side brake for safety). The road assessment usually begins in a parking lot and progresses to higher levels of traffic. The on-road driving assessment looks at how well the individual manages the car in traffic, visually attends to and scans the surroundings, maintains good lane positioning, follows the rules of the roads, yields to oncoming vehicles, and plans and makes everyday driving decisions. Once both the clinical and on-road driving assessment are completed, the occupational therapist can provide recommendations back to the individual, family, and physician regarding driving safety.

Adapted from an article that first appeared in St. Louis APDA LiNK, Newsletter of the American Parkinson Disease Association, St. Louis (MO) Chapter, August 2012: Volume 26, Issue 3. Used with permission from Peggy P. Barco, MS BSW OTR/L, Author, and Deborah D. Guyer, Editor.



2012 Parkinson's Unity Walk Raised Over \$1.8M for Parkinson's Research

Photos by Ed Miville



Over 10,000 people participated in this year's walk along a gentle 1.4 mile wheelchair accessible route. The event also features informational booths including "Ask the Doctor," Unity Walk sponsors, and representatives of the APDA and the other six major US Parkinson's foundations that receive funds from the event. Vendors provide tasty food on-site.

1. The Unity Walk is an annual Parkinson's Awareness Month event in Central Park, New York City that raises funds for research that will improve the quality of life of people living with Parkinson's disease and lead to the discovery of a cure. The 18th Unity Walk on April 28, 2012 raised over \$1.8 million that was divided evenly among seven organizations: *American Parkinson Disease Association, The Michael J. Fox Foundation for Parkinson's Research, National Parkinson Foundation, Parkinson's Action Network, The Parkinson Alliance, Parkinson's Disease Foundation and The Parkinson's Institute and Clinical Center.*
2. Helaine Isaacs, Event Director, Parkinson's Unity Walk had a lot to smile about: Her year-long planning with volunteers, donors/teams, corporate sponsors and more resulted in another successful fundraiser for research!
3. The walk started at the 72nd Street Bandshell in Central Park. Michael J. Fox was one of the welcoming speakers. He pointed out, "Too many clinical trials finish late because of trouble recruiting volunteers. That means we all have to wait longer for new treatments and new cures." He encouraged each person, whether with PD or not, to sign up with Fox Trial Finder (www.FoxTrialFinder.org) to find a clinical study for which you might volunteer.
4. The New Hampshire-based "Shufflebugs" team includes family members Jennifer Snyder, Ed Miville, Victoria Hill, and Mike Miville (left to right).

To watch a fun, four-minute long video of the Parkinson's Unity Walk (including remarks by Michael J. Fox), visit vimeo.com/41972025, courtesy of Michael Miville (www.mivillephoto.com).

Thank You to Our Donors

We thank all who have made donations in honor and in memory of their beloved family and friends with Parkinson's. *To make donations, please make checks payable as indicated and send to the address listed:*

To support the Parkinson's Center at DHMC (an official APDA Information and Referral Center):

Check payable to:
Hitchcock Foundation-Parkinson's

Mail to:
Hitchcock Foundation-Parkinson's
DHMC
One Medical Center Drive
Lebanon, NH 03756

To support the NH Chapter of the APDA:

Check payable to:
APDA NH Chapter

Mail to:
APDA NH Chapter
PO Box 831
Londonderry, NH

To support the National Office:

Check payable to:
APDA, Inc.

Mail to:
APDA, Inc.
135 Parkinson Avenue
Staten Island, NY 10305

Levodopa, Melanoma and Parkinson's Disease: Is There a Connection?

LEVODOPA WAS APPROVED as a treatment for Parkinson's disease in 1968 by the US Food and Drug Administration. In the form of carbidopa-levodopa (Sinemet®), it remains the most common treatment for Parkinson's nearly 45 years later.

In 1972, the case of a PD patient who was treated with levodopa and suffered recurrent malignant melanoma skin cancer was reported. Other cases were subsequently published, and by 1976 it was announced that use of levodopa in Parkinson's patients with melanoma was contraindicated.³ However, studies had not answered the question: Was the occurrence of melanoma in Parkinson's patients actually caused by levodopa, or was it a coincidence?

At the time, it seemed plausible that there could be an association between levodopa treatment and melanoma incidence: Levodopa is the substrate for the synthesis of both dopamine and melanin, which is the substance that accumulates in the darkly pigmented cells of melanoma.^{2,3,6}

Numerous studies¹⁻⁶ have now shown that people with Parkinson's are at higher risk for melanoma, but that the increased incidence of melanoma is not related to any PD medication. Instead, it appears that "melanoma and PD might have

shared environmental or genetic risk factors or pathogenic pathways."⁴

Surprisingly, the Physician's Desk Reference (PDR) still states that carbidopa-levodopa is contraindicated for those with undiagnosed skin lesions or a history of melanoma! It is no wonder that many in the Parkinson's community, as well as numerous medical personnel who do not specialize in PD, still believe that there is a causal link between levodopa and melanoma. Unfortunately, many who would have received relief of their PD symptoms by taking levodopa have avoided this medication for fear of getting melanoma.

More on Melanoma from the National Institutes of Health (NIH)⁷:

A mole, sore, lump, or growth on the skin can be a sign of melanoma or other skin cancer. A sore or growth that bleeds, or changes in skin coloring may also be a sign of skin cancer.

The ABCDE system can help you remember possible symptoms of melanoma:

Asymmetry: One half of the abnormal area is different from the other half.

Borders: The edges of the growth are irregular.

Color: Color changes from one area to another, with shades of tan, brown, or black, and sometimes white, red, or blue. A mixture of colors may appear within one sore.

Diameter: The spot is usually (but not always) larger than 6 mm in diameter – about the size of a pencil eraser.

Evolution: The mole keeps changing appearance.

The key to successfully treating melanoma is recognizing symptoms early. You might not notice a small spot if you don't look carefully. Have yearly body checks by a dermatologist, and examine your skin once a month. Use a hand mirror to check hard-to-see places. Call your doctor if you notice anything unusual.

The NIH also states that the risk of developing melanoma increases with age, and that you are more likely to develop melanoma if you:

- Have fair skin, blue or green eyes, or red or blond hair
- Live in sunny climates or at high altitudes
- Spent a lot of time in high levels of strong sunlight, because of a job or other activities, or use tanning devices
- Have close relatives with a history of melanoma

Some Take-Home Messages

- Levodopa treatment is not associated with an increase in diagnosis of melanoma or other cancers.
- People with Parkinson's
 - have an estimated 2- to 6-fold increased risk of melanoma
 - have a reduced risk of most other types of cancer

Melanoma is rare in the general population (based on 2007-2009 data, only 2% of those born today will be diagnosed with melanoma in their lifetimes⁸). The estimated lifetime melanoma rate for those with PD is therefore 4-12%.

- Malignant melanoma is a curable disease if treated early. If left untreated, it is potentially fatal.

REFERENCES:

1. Bertoni JM, Arlette JP, Fernandez HH, et al. Increased melanoma risk in Parkinson disease: a prospective clinicopathological study. *Arch Neurol* 2010; 67:347-352
2. Driver JA, Logroscino G, Buring JE, et al. A prospective cohort study of cancer incidence following the diagnosis of Parkinson's disease. *Cancer Epidemiol Biomarkers Prev* 2007; 16: 1260-1265
3. Ferreira JJ, Neutel D, Mestre T et al. Skin Cancer and Parkinson's Disease (Review). *Movement Disorders* 2010; 25: 129-148.
4. Liu R, Gao, X, Lu Y, Chen, H. Meta-analysis of the relationship between Parkinson disease and melanoma. *Neurology* 2011; 76: 2002-2009
5. Weiner WJ, Singer C, Sanchez-Ramos JR, Goldenberg JN. Levodopa, melanoma, and Parkinson's disease. *Neurology* 1993; 43: 674-677
6. Zannetti R, Rosso S, Loria DI. Parkinson's Disease and Cancer (Commentary) *Cancer Epidemiol Biomarkers Prev* 2007; 16: 1081
7. www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001853/ (accessed August 8, 2012)
8. seer.cancer.gov/statfacts/html/melan.html (accessed August 8, 2012)





April was Awareness Month for Parkinson's disease. Our final event was a Candle Light Vigil in Concord.

The Honorable Laurie Harding, a NH State Representative from Lebanon, our guest speaker, addressed the concerns of families, caregivers and people with Parkinson's. She spoke eloquently and knowledgeably about neurological diseases and awareness events.

The morning of the vigil an email came to me announcing that the tandem bike and the rider would not be attending. Our programs had been printed and sent. Many people had called to say they were coming specifically to see that demonstration. Riding a tandem bicycle requires practice and faith in the person in front. On a moment's notice, Goodale's Bicycle Shop in Concord lent us a new tandem bike and Fred borrowed a pickup truck to transport it but we did not have a rider. I was willing to be on the back but no one volunteered to ride in front controlling the tandem.

Unexpectedly, a young family friend arrived with her husband, Eric. He is an avid biker and volunteered to be in front. I was the pedaling passenger. Steven Mollohan spoke about benefits the tandem bike has for people with PD, as we demonstrated. When the demo ended the rain poured down. Everyone retreated under the portico. Bill Brawley spoke about DBS and Victoria Tane presented her tulip jewelry designed for Parkinson's Awareness Month. We recited the "Parkinson's Pledge", lit our candles in the wind, and sang "You Raise Me Up!"

Thanks to everyone who attended the Candle Light Vigil at the Capitol in spite of the damp, chilly weather, to Laurel for the refreshments, to all our speakers and to Eric for the demonstration.

Maureen M. Chamberlain
NH Chapter President, APDA

ANNOUNCEMENTS AND EVENTS

From the APDA Parkinson's Information and Referral Center at Dartmouth-Hitchcock Medical Center

For information, please contact Diane L. Church at (603) 653-6672 or send email to Diane.L.Church@hitchcock.org

September 15, 2012 (starts 10 am)
3rd Annual Walk-in-the-Park, by the APDA New Hampshire Chapter
Greeley Park, Nashua, NH
All proceeds benefit APDA Parkinson's research grants. Contact: Maureen Chamberlain at (603) 434-6252 or email mchamberlain.apdanh@gmail.com

Saturday, October 1, 2012
Deadline for ordering Parkinson's tulips as part of the American Parkinson Disease Association's Garden of Hope project. The APDA receives 40% of the proceeds, and you will enjoy the beautiful red tulips as you spread awareness of PD! Order tulip bulbs from www.tulipworld.com/apda/ or phone TulipWorld LLC at (866) 688-9547.

Saturday, October 13, 2012
"Positive Approaches to Parkinson's," A Symposium for People with Parkinson's, Caregivers, and the Community, SERESC Conference Center, Bedford, NH
Presentations by Janet Edmunson, MA and Benjamin Wolozin, MD, PhD; Creativity Gallery: Art By and For People with Parkinson's. Fee of \$15 per person includes continental breakfast and lunch. Space is limited. Pre-registration must be received by October 3.

Sunday and Monday, November 4 & 5, 2012
New England Regional Biennial Parkinson's Conference, Sturbridge Host Hotel, Sturbridge, MA, includes Sunday evening Dinner Dance. Sessions include "Ask the Expert: Update on the Management of Parkinson's," with Samuel Elias, MD, PhD, Stephen L. Lee, MD, PhD, David B. Sommer, MD, MPH; "Common Problems with Updated Solutions," with Joseph Friedman, MD, Anna Hohler, MD, and Terry Ellis, PT, PhD, NCS; "Got Parkinson's? What you CAN do," with Pamela Quinn, Renee LeVerrier, and Michael Achin. Brochures to be mailed, registration required. For more information, contact (800) 651-8466 or information@apdama.org

Wednesday, December 5, 2012, 1:30 – 2:30 pm .
Parkinson's Disease Question and Answer
Dartmouth-Hitchcock Aging Resource Center, 46 Centerra Parkway, Lebanon, NH; broadcast by live video to Horse Meadow Senior Center in North Haverhill, NH
Facilitators: David J. Coffey, MD; Stephen L. Lee, MD, PhD; Diane L. Church, PhD
Parkinson's symptoms, progression, and responses to treatment vary from person to person to such an extent that some have called Parkinson's a "designer disease." Join this question-and-answer session to learn more about Parkinson's disease and the resources available through the Parkinson's Center. Free of charge, but advance registration required. For more information or to register, phone (603) 653-3460 or email AgingCenter@hitchcock.org

Tuesdays and Fridays, September 11 – October 19 (12 classes), 11:30 am – 1:00 pm
Parkinson's Wellness Program (Six-week program)
Dartmouth-Hitchcock Medical Center, Lebanon, NH
(with pre- and post-assessments the weeks before and after)
Exercise, balance, gait training, and education program to help those with PD achieve a better quality of life. "Medical Eligibility Form" is required to ensure that the program is appropriate and safe for you. \$250 per person; scholarships are available

Tuesdays and Thursdays, September 11 – October 25 (14 classes), 4:30 – 6:00 pm
Parkinson's Disease Community Exercise Group
Northeast Rehabilitation Hospital Network, Salem, NH
Exercise and education to help you in your fight against Parkinson's disease; \$274 per person due September 11
Please call (603) 681-3210 to schedule a free screening on Wednesday, August 29 or Wednesday, September 5 or to request more information.

2012 Membership Drive

Join the New Hampshire Chapter of the APDA!



Please help your NH Chapter of the APDA reach its goals of raising funds and increase awareness to help fight Parkinson's disease.

We hope to develop and fund local programming, such as dance and exercise classes, educational events, respite care, travel costs for people who no longer drive, and more. But we can't do it without your help!

Please join us:

- Lend your financial support to the work of the Chapter through payment of modest annual dues (\$20 per household).
- Share in the efforts and fun to help us reach the important goals of the Chapter. You might volunteer at a fundraising event, participate on a committee, help educate the community about Parkinson's, and more! We welcome your ideas.
- Attend Chapter Board Meetings: held on the second Wednesday of most months, 6:00 p.m., Elliot Senior Health Center, Manchester, NH. All Chapter Members are welcome to attend. The Chapter leadership appreciates your input and support.

Name _____ Date _____

Address _____

(Please affix address label if you prefer!) 

Phone # (____) _____ E-mail _____

Please indicate your level of support:

Household Membership	\$20 annual _____
Household Membership with Additional Donation	Please indicate total: \$ _____
Other donation	Please indicate amount: \$ _____
Corporate Sponsorship	\$25 _____ \$50 _____ \$100 _____ Other _____

Do you belong to a Support Group? Please tell us which one _____

How would you like to see your membership dollars used? _____

Do you have a fundraising idea that might help us achieve our goals? _____

Do you have skills, time and/or resources that you would like to contribute to our efforts?

____ Chapter Board membership

____ Becoming an event coordinator, assistant or volunteer

____ Helping with public relations and advocacy

____ Other (please describe) _____

Thank you for your interest and support!

How does someone become a member of the New Hampshire Chapter of the APDA?

Kindly complete the form on this page.

Please make checks payable to
NH Chapter APDA

Mail to the following address:

NH Chapter APDA
PO Box 183
Londonderry, NH 03053

We are a nonprofit 501(C)(3) organization. All donations and dues are tax deductible. For more information, contact Maureen at (603) 434-6252 or email mchamberlain.apdanh@gmail.com.

PARKINSON'S COMPANION IS A PUBLICATION OF THE PARKINSON'S CENTER AT DHMC

The Parkinson's Center at Dartmouth-Hitchcock Medical Center is an Information & Referral Center of the American Parkinson Disease Association, Inc

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This newsletter is intended solely to provide you with information on Parkinson's disease. You should not make any changes in your treatment without first discussing them with your healthcare provider.



Dartmouth-Hitchcock
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Attention: Diane L. Church

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