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# Parkinson's companion

 Dartmouth-Hitchcock

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## Voices of Parkinson's: Bodies of Evidence BY MARILYN MCGUIRE

**Wine, cheese and leather** are the only things people like to have age or show signs of wear. Otherwise we fight to prevent breakdown or damage. We rustproof, weatherproof, and sunblock. We ScotchGuard, childproof, waterproof and pestproof. We fireproof, weedproof, wrinkleproof and StaticGuard. We spend lots of time and money on protection. Proof means "to make impervious to penetration and ill effects", according to Oxford. Proof is also a body of evidence that demonstrates the truth of something.

In this final article of my Soul Series (see newsletters Spring and Fall 2016), I offer

proof that soulful activity makes one's soul impervious to ill effects of age and disease. I present the experience of two former clients as a body of evidence that this activity promotes a feeling of well-being as reported by them and their families. Their circumstances differ but each tells a story of how life can have meaning and joy in spite of changing circumstances. It does not matter whether Parkinson's disease, Alzheimer's disease, or diabetes is trying to permeate your well-being, or at what age changes occur. We must stay engaged in activities we love to be whole and well. Here are my bodies of evidence.

**Dee**  
AT 92, DEE PROVIDED the wheels for a trip to Bingo. Gambling on horses, dogs, sports and Bingo was her soulful activity. Gambling was never a problem; it was a social event. She dressed up, gathered her friends and headed out.

The last time she went to a Bingo hall she made a small mistake that changed her life. She got up from the table to go to the ladies' room and forgot to take off her reading glasses. They distorted her perception. She fell hard and broke her shoulder. This injury led to surgery, a lengthy rehab stay and ultimately the loss

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of her driver's license due to decreased mobility in her shoulder. Having no wheels stopped her in her tracks.

Her daughter called me concerned that her Mom was withdrawn and depressed. Alone in her apartment much of the time, her appetite decreased and she lost weight. Mild signs of dementia surfaced. I began to visit her. As I became familiar with her situation, something really surprised me. The facility where she lived offered weekly Bingo but Dee never attended.

When I asked her about this she said she would never go to Bingo again. She was afraid she would fall. To me it seemed like PTSD from her recent ordeal. Also she had never played Bingo with this group of relative strangers. I offered to accompany her but she was not interested. I persisted by mentioning Bingo now and then.

"Oh no. I can't do that. I don't want to fall. It was so embarrassing," Dee told me. Eventually she added, "I don't remember how to play."

Dee was losing ground fast. If you can't bring a person to Bingo then bring Bingo to the person, right? I introduced the idea of bringing a Bingo game to her. She was not interested at first. Then one day when I told her I had the game in my car she asked me to bring it in. I had an old-fashioned game with a metal cage and little wooden balls with numbers painted on them. There were Bingo cards with poker chips for markers. I set it up on her kitchen table. Still Dee declined to play repeating that she did not remember how. Dee agreed however to **let me try the game** when I told her I needed to make sure everything was in working order.

It was the sound...the classic sound produced by the wooden balls tumbling in

the cage...rattle, rattle, rattle. If you close your eyes you can hear the balls going round and round in the cage. I stopped spinning and let a ball plunk into the holder. I read the number in Bingo caller fashion. I placed a chip on my Bingo card. Dee watched from afar at first. I turned the cage again...rattle, rattle. Dee came over and sat with me so I put a card in front of her. I called the number and she placed a marker on her card.

From then on, we played nearly every visit. I never convinced her to go to the facility Bingo game but I saw the joy in her face as she played at home. One time when I forgot to bring the game in with me, she immediately asked me where it was. Dee's daughter reported that her Mom enjoyed our time together.

## Theresa

Have you ever known someone who smiled with her whole face? Theresa had an ear-to-ear grin that lit up her dazzling blue eyes. Her soul sparkled from behind those eyes especially when someone came to visit her.

Physically Theresa was very healthy. Lifelong moderation had served her well. She was tall, slender and an enthusiastic walker. As preserved as her body was, her mind suffered decay from Alzheimer's disease. Walking turned to wandering, discipline turned to obsession, friendliness and warmth turned to unsafe encounters with strangers. Out of fear that she would wander out into a world of unknown danger, her family asked me to help. Classical music on the radio, knobs off the stove and post-it reminders were no longer enough to keep her safe. She needed supervision, which I hoped to

combine with time for soulful activity.

Theresa was an avid seamstress. She made all of her daughters' clothes as she raised them. She loved fashion catalogues and magazines, which is where we started. She could no longer follow a sewing pattern but liked looking at books of them. Soon we ventured out to a fabric store where we were greeted by lively colors and patterns and the musty smell of bolts of fabric. Theresa was at home here. Each time she caressed the fabrics, her smile validated that she was feeding her soul. We also found buttons-so many buttons of all shapes, colors and sizes! The family and I put a collection of buttons in a big coffee can so Theresa could enjoy them at home (supervised). Theresa's daughter confirmed the benefit of these activities, reporting that Theresa was sleeping much better at night after our outings. Theresa's smile confirmed it too. It was worth a million bucks and I was the richest woman in the world to know her.

These are just two examples of proof that soulful activity pays off, two bodies of evidence. All of us, even if we are caregiving, must take time for soulful activity to preserve our well-being. *It renews a familiar sense of joy and contentment.* It prevents physical and mental breakdown. Just as we rustproof our cars, waterproof our boots, and sunblock our skin, we must weatherproof our souls against life's storms. ●

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Marilyn McGuire is an eldercare nurse who feeds her soul by writing and speaking about a holistic approach to dementia care. She is founder of Alzheimer's Creative Care. Contact her at [pmcrackerbarrel@gmail.com](mailto:pmcrackerbarrel@gmail.com)



# Parkinson's Disease Resources

**American Parkinson Disease Association**  
www.apdaparkinson.org  
800.223.2732

**APDA Rehab Resource Center at Boston University**  
www.bu.edu/neurorehab/resource.center  
888.606.1688

**ClinicalTrials.gov**

**Dance for PD®**  
danceforparkinsons.org  
800.957.1046

**Dartmouth.Hitchcock Parkinson's Disease and Movement Disorders Center**  
www.dartmouth.hitchcock.org/parkinsons  
603.653.6672

**Davis Phinney Foundation for Parkinson's**  
www.davisphinneyfoundation.org  
866.358.0285

**HealingWell.com**  
www.healingwell.com/parkinsons

**Home Remodeling for Disability and Special Needs**  
www.expertise.com/home.and.garden/home.remodeling.for.disability.and.special.needs

**Job Accommodation Network**  
askjan.org/media/PD.html  
800.526.7234

**LSVT Global (LSVT BIG and LOUD)**  
www.lsvtglobal.com  
888.438.5788

**Michael J. Fox Foundation for Parkinson's Research**  
www.michaeljfox.org  
800.708.7644

**National Parkinson Foundation**  
www.parkinson.org  
800.473.4636

**Our Parkinson's Place**  
ourparkinsonsplace.blogspot.com

**Outdoor Mindset**  
www.outdoormindset.org  
email: connect@outdoormindset.org

**Parkinson's Action Network (PAN)**  
michaeljfox.org/policy

**Parkinson's Comfort Project**  
parkinsonscomfort.org  
email: ParkinsonsComfort@gmail.com

**Parkinson's Disease Foundation**  
www.pdf.org  
800.457.6676

**The Parkinson Alliance**  
www.parkinsonsalliance.org  
800.579.8440

**PD Gladiators**  
pdgladiators.org  
770.450.0792

**Rock Steady Boxing**  
www.rocksteadyboxing.org  
888.217.0577

**U.S. Department of Veterans Affairs**  
www.parkinsons.va.gov  
Contact your nearest VA facility.

**Frederick C. Binter Parkinson's Disease and Movement Disorders Center University of Vermont Medical Center**  
www.uvmhealth.org/medcenter/Pages/Departments.and.Programs/Movement.Disorders.aspx  
802.847.4589



## A Note from the Coordinator: Diane L. Sherman, PhD

Dear friends,

Spring is here! Each year, April is declared "Parkinson's Awareness Month" by the United States Senate. It is hoped that the national designation of Parkinson's Awareness Month will build awareness of Parkinson's disease and the Parkinson's community through educational events and media coverage.

In this newsletter, we wrap up our "Soul Series" by Marilyn McGuire, get some tips on asking for help (important for both those with Parkinson's and their care partners!), and learn more about the common occurrence of Parkinson's disease psychosis. If there are topics of interest to you that you would like featured in the Parkinson's Companion, or if you enjoy writing and would like to contribute, please get in touch and let me know!

Best wishes,

*Diane*



# Psychosis in Parkinson's:

*now we can treat it without making other symptoms worse*

Half of people with Parkinson's disease experience hallucinations, paranoia and delusions. Mary O'Hara reports on a new hope.

On 29 April 2016, the US Food and Drug Administration (FDA) approved the first ever drug to specifically treat delusions and hallucinations associated with Parkinson's disease psychosis (PDP). Trials showed that Nuplazid™ (pimavanserin) eased the symptoms of the condition without the same negative effects on motor symptoms as other antipsychotic drugs.

One night without warning, Jay Sagen leapt from his bed and grabbed the quilt, then ran downstairs and threw it out onto the street. He was certain there was a large black snake in it. His startled wife Diane hurried after him and tried to explain that nothing was there.

Then Jay began seeing black cats everywhere in the house. He believed there were groups of people on the property at night too, and that a creature called Big Boy was in their bed with them. Sometimes, he believed he'd whiled away whole afternoons talking to his brother in the living room of their cozy California home. He simply didn't understand when Diane told him his brother was never there.

Jay, a 77-year-old artist, taught for decades at local community colleges. He was diagnosed with Parkinson's disease (PD) in 2009 after a neurologist observed his tremors and other physical symptoms, including stiffness. Diane, a therapist now aged 73, was not scared: "We'll deal with it, if that's what it is," she thought.

Preparing for the tough adjustment to life as the primary caregiver to a person

with a neurodegenerative illness, Diane knew the disease was associated with health problems ranging from difficulty sleeping to tremors and slowing of movement. She also expected that it would take a toll on her time and energy as she assisted Jay with his physical impairments.

What she didn't know—and what few people even within the medical and caring professions realize—is that over the course of their illness at least half of all people diagnosed with PD will develop another set of symptoms known as Parkinson's disease psychosis (PDP). The impact on the patient and family—often because they don't know what is happening—can be devastating.

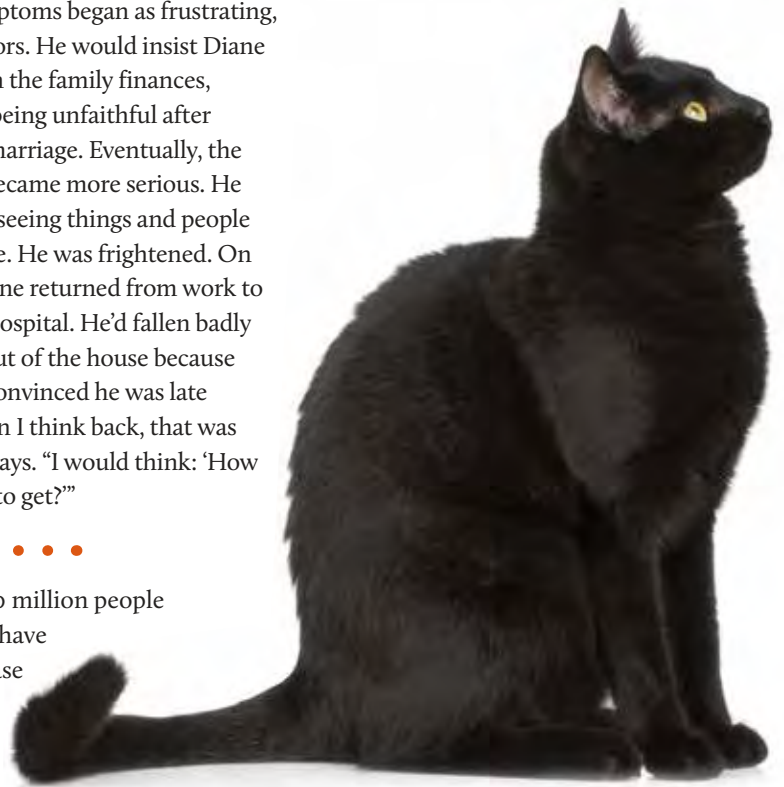
Jay's PDP symptoms began as frustrating, annoying behaviors. He would insist Diane was stealing from the family finances, or accuse her of being unfaithful after 50-odd years of marriage. Eventually, the manifestations became more serious. He was increasingly seeing things and people that weren't there. He was frightened. On one occasion Diane returned from work to learn Jay was in hospital. He'd fallen badly while charging out of the house because he had become convinced he was late for a party. "When I think back, that was disturbing," she says. "I would think: 'How bad is this going to get?'"



Between 7 and 10 million people are estimated to have Parkinson's disease worldwide. This means several million people

will also develop PDP and experience sometimes debilitating delusions and hallucinations. Yet while experts acknowledge that general awareness of the motor symptoms of Parkinson's is high, PDP remains largely hidden, misunderstood and undertreated.

Dr. Rachel Dolhun points out that it can be difficult for people to make the connection between PDP symptoms and Parkinson's, and to talk openly about it. "PDP has symptoms that people don't recognize, that they don't bring up to their doctors and to their caregivers... they're afraid they're going crazy. There are things that we can do—but we can't do anything if you don't tell us about it."



It isn't clear exactly what causes it, but the psychosis can stem from either the underlying Parkinson's disease or the medication used to treat it. Drugs prescribed to alleviate the motor symptoms of Parkinson's work by replenishing dopamine, the brain chemical that is diminished in people with the disease. The problem is that while this can reduce motor symptoms, increasing dopamine can overstimulate other parts of the brain and cause psychosis.

Meanwhile the medications most commonly used to treat psychosis symptoms—drugs such as clozapine—act by blocking the dopamine system, which tends to worsen motor problems as well as run the risk of serious side-effects.

Dr. Jeffrey Cummings sums it up this way: "The great paradox is that the drugs that improve psychosis make Parkinson's worse. And so we just have not had a good alternative for our patients in terms of controlling psychosis."



Pressure on marriages and other relationships are recurring characteristics of living with PDP, not least because paranoia about infidelity features so highly. Dr Jim Beck says the "ripple effect" on the wider family and loved ones is significant. "The psychosis, as it gets more severe, can be really disruptive for relationships and for caregivers. That's the number one reason people with Parkinson's enter nursing homes. It's because of psychosis."

Elaine Casavant is a longstanding advocate on behalf of people with PDP and their families. A former nurse, she is a member of the People with Parkinson's Advisory Council and speaks across the USA on the subject. She says the difficulties of living with and treating PDP should be much more visible and a higher priority for policymakers, researchers and medics.

Elaine's husband Len was diagnosed with Parkinson's in the early 1990s when he was in his mid-40s. His psychosis symptoms, initially wrongly diagnosed as dementia, have waned at times as some medications and interventions, such as

deep brain stimulation, have produced temporary relief. But on the whole, she says, the accusations of infidelity and the delusions and hallucinations have taken their toll. "They're odd, they're hurtful, they're frightening," she says.

One night, Len got up thinking children were playing in his room. Elaine heard him shouting in the night and ran into the room. But Len had strung an extension cord across the doorway. As she tripped and fell, he started yelling: "Elaine, Elaine, I've got one!"

On 29 April 2016, the US Food and Drug Administration (FDA) approved the first ever drug to specifically treat delusions and hallucinations associated with PDP. Trials showed that Nuplazid™ (pimavanserin) eased the symptoms of the condition without the same negative effects on motor symptoms as other antipsychotic drugs.

Nuplazid™ is the first example of a class of drugs called selective serotonin inverse agonists. "It does not work on the dopamine receptors. It works on the serotonin pathways," explains Dr. Dolhun. "So it has this new mechanism of action."

Dr. Cummings, a lead researcher on the trial, says that the new drug is a game changer. "It's a breakthrough compound because not only have we not had any treatment for psychosis in Parkinson's disease, we haven't had treatment for psychosis in any neurological disease."



Ruth Ketcham was one of the people who took part in the phase III trial of Nuplazid™. Her hallucinations had begun one year after her diagnosis with Parkinson's. At first, her daughter Jody Wade explains, it was a belief that animals were in the house at night. "I said, 'What kind of animals?'" An exterminator confirmed there were none.

The alarm bells began ringing louder when Ruth started repeating a story about the neighbors doing T'ai Chi in the garden every morning at daybreak. "She described people in amazing detail and the detail never changed." Only after Jody stayed overnight at the house did she realize it was an elaborate hallucination.

More than five years later, and now

93, Ruth is still taking the drug and the outcome has been dramatic for the whole family. Within weeks, the hallucinations had drastically reduced, and while there are some mild symptoms now and again, they are nothing like before.

"I ask my mother: 'What does this mean to you? What do you take away from this?' And she says: 'It gave me a normal life back.' Five years later I still cry talking about it. It gave us years with my mother that we wouldn't have had."

Like any drug, Nuplazid™ has various possible side-effects. Adverse reactions recorded in the trials included a small number of participants experiencing nausea, constipation and confusion—luckily, Ruth has experienced none of them.

A few weeks into Jay Sagen's first prescription of Nuplazid™, Diane noted some positive signs in her diary. "It's sort of sporadic," she confirmed. "He'll have a couple of days with no delusions, then a day with lots of them. I notice a difference though. He'll point to what he thinks is a man (usually in the mirror) and say something about him. All it takes is for me to say, 'There's no man,' and he'll say, 'Oh,' and drop it. So he's easier to bring around to reality than he was."



A month later, in a further update, she explained that things were continuing to improve: "The Nuplazid is working really well. He only sees the occasional phantom person now." ●

**For more information on Nuplazid™, speak with your neurologist and visit [www.nuplazid.com](http://www.nuplazid.com).**

The original article by Mary O'Hara first appeared in Mosaic magazine on November 29, 2016 and is republished here under a Creative Commons license. This article has been excerpted with permission from Mosaic Science. Any errors of omission or inadvertent alteration of context are the responsibility of the editor of Parkinson's Companion. To read the complete article, please visit: <https://mosaicscience.com/story/parkinsons-disease-psychosis>

# Learning to Ask Others

**Many of us are happy to help others when they need help, but often we are reluctant to ask others for help when we need it. How to overcome your reluctance to ask for assistance.**

**It's 4:30 on a brisk November afternoon in New York.** I am hoping to hail a cab home but every passing taxi is either taken or "off duty." Thinking I might have better luck at a busier intersection, I head toward the corner where, three steps from the curb, I freeze—unable to move backward or forward. (Dammit, it's my Parkinson's acting up.) Anxiety keeps me rooted to the spot as people rush by. What to do? Summoning all my courage, I waylay a thirty-something woman, and tell her about my Parkinson's, half-expecting her to say, "Sorry, I'm really late." But she doesn't beg off. Instead, she snakes her

way through the slow-moving traffic and, finding no available cabs, she flags down an empty limo and tells the driver about what has now become "our" problem. Will he help? She's quite persuasive and I hold my breath 'till he says "Yes." Two strangers this day have taught me an important lesson: It's okay to ask for help.

Which is not to say that it's easy. Many of us are happy to help others, yet have a hard time being on the receiving end. Motivational speaker Mike Robbins says, "I will frequently ask the audience, 'How many of you like helping other people?' And almost everybody in the room raises their hand. The next question I ask is, 'How many of you like asking other people for help?' And maybe ten percent of hands go up."

Why do so many of us resist asking for help when we need it? I decide to find out.

**Fear of being viewed as vulnerable:** "Requesting support can make us feel vulnerable," says Robbins. "We usually

think that we should be able to do everything ourselves and by admitting that we need help, we are somehow being needy or incompetent. For men, especially, there's a lot of fear of any perception of being weak. In fact, asking for help is not an indication of weakness; it's a sign of strength."

**Fear of rejection:**

But what if we ask and the person we approach turns us down? The fear of being rejected leads many of us to go it alone. However, according to a study by Francis Flynn and Vanessa Bohns, we dramatically *underestimate* how likely others are to help us. Most people will comply with a direct request for help.

**Fear of the loss of control:**

"Getting someone to help might mean the job won't be done the way I like." Many of us are unwilling to cede power to others. During my career as a freelance writer, there have been times when I had to juggle multiple deadlines. Refusing to hire someone to transcribe my many tape-recorded interviews, I stayed up late, slept late, and played havoc with my family's plans and schedules. But, I explained, nobody else was capable of interpreting the pauses on the tapes.

**We don't ask because we think that people ought to know:**

Clarisse, 53, is a good daughter—she takes personal days off from work to escort her mother to medical appointments, rushes home each evening to check on her mom and spends weekends tending to her mother's needs: cooking, cleaning and playing endless rounds of Rummy 500 to help the time go by. She bundles her mother up and gets her to church every Sunday.



# for Help

BY CLAIRE BERMAN  
ADAPTED FROM A RECENT ARTICLE  
PUBLISHED IN NYCITYWOMAN.COM

"I can't remember the last time I went to a movie or met friends for lunch," Clarisse says. "It would be wonderful if some of the church ladies could spend a Saturday afternoon with my mom." Has she asked them for help? "No," she tells me, "They can see what the situation is." If she truly wants help, however, she will have to ask for it.

## Guidelines on making it easier to ask others for help:

- First and foremost, you have to ask!
- Be as specific as you can about what you need and how much time it may involve.
- In so far as is possible, be flexible: If the person you ask cannot make it on Monday, will another day work?

- Politely provide an out such as: "I understand that you're busy and may not be available..."
- If they accept, try not to micromanage. Allow some leeway. Nobody will do it exactly your way. And you may even learn something!
- Tell the help giver that you truly value her or his assistance. In short: Say thank you—a lot.

This article was adapted from the original and used with permission of the editor of NYCITYWOMAN.COM and the author. Claire Berman has written nine books and was a contributing editor at New York magazine and has written for The New York Times magazine, Parade, Reader's Digest, and other national magazines.

## ANNOUNCEMENTS & EVENTS

### APDA Vermont Chapter's Parkinson's Awareness Day: "Living with PD: An Integrative Approach"

Saturday, April 22, 9 am to 4 pm

THE QUECHEE CLUB, QUECHEE, VT | \$20  
With Deborah Black, MD; Suzanne Kennedy, MD; Maureen Vinci, Chapter President; Gale Golden, LICSW, BCD; Timothy Fries, MD; and M. Sara McMahon. Presentations on cognition, depression, "Performance, Pleasure and Procrastinating," dysautonomia, and movement for Parkinson's.

For more information or to register, call 802.847.3366 or go to [parkinsonsvt.org](http://parkinsonsvt.org).

### APDA Vermont Chapter 8th Annual Optimism Walk Saturday, May 13

STOWE MOUNTAIN RESORT, STOWE, VT  
For more information, call 802.847.3366 or email [parkinsoninfo@uvmhealth.org](mailto:parkinsoninfo@uvmhealth.org)

### Parkinson's Educational Event for Patients, Caregivers and the Community: *Parkinson's Disease: Where we are and where we've been*

Monday, June 19, 8:30 am to 3 pm

COURTYARD MARRIOTT, DOWNTOWN KEENE, NH | \$20;  
REGISTRATION FORMS AVAILABLE LATER THIS MONTH.

Speakers: Stephen L. Lee, MD, PhD, movement disorders specialist; Heintje Calara, RN, Parkinson's nurse and doctoral candidate; Marilyn McGuire, BSHS, LPN, eldercare nurse and educator; and Donna Brooks, BS, RSMT, ERYT, movement and yoga specialist.

Contact: Parkinson's Center at 603.653.6672 or email [Diane.L.Sherman@hitchcock.org](mailto:Diane.L.Sherman@hitchcock.org)

We are grateful to all who have made donations in honor and in memory of their beloved family and friends and in support of the Parkinson's Center at Dartmouth-Hitchcock.

## TO SUPPORT THE PARKINSON'S CENTER:

### DONATE BY CHECK:

Please make check payable to: "Hitchcock Foundation," noting "Parkinson's" in the memo line.

### Please send to:

Hitchcock Foundation  
One Medical Center Drive  
Lebanon, NH 03756

### DONATE BY CREDIT CARD:

Enter your donation information at: [http://med.dartmouth-hitchcock.org/hitchcock\\_foundation/donate\\_now.html](http://med.dartmouth-hitchcock.org/hitchcock_foundation/donate_now.html)

Specify Parkinson's Center in the box: "Name of fund, program or doctor"

## TO SUPPORT PARKINSON'S RESEARCH AT DHMC:

### Please go to our webpage:

[www.dartmouth-hitchcock.org/parkinsons](http://www.dartmouth-hitchcock.org/parkinsons) and click on the "support Parkinson's research at DHMC" link in blue.

## FOR HELP WITH OTHER TYPES OF GIFTS,

Please contact the DHMC Development Office:

603.653.0759

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### Dartmouth-Hitchcock

Department of Neurology  
One Medical Center Drive  
Lebanon, NH 03756  
603.653.6672

[Diane.L.Sherman@hitchcock.org](mailto:Diane.L.Sherman@hitchcock.org)  
[www.dartmouth-hitchcock.org/parkinsons](http://www.dartmouth-hitchcock.org/parkinsons)

### Coordinator/Editor:

Diane L. Sherman, PhD

### Medical Directors:

Mary S. Feldman, DO  
Stephen L. Lee, MD, PhD

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 health care provider.



**Dartmouth-Hitchcock Medical Center**

One Medical Center Drive  
Lebanon, NH 03756-0001

**Attention: Diane L. Sherman**

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