



Mr. G Goes to the Hospital: A story of Gulash, grit, and gratitude

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Parkinson's companion

 Dartmouth-Hitchcock

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Voices of Parkinson's: Ruby and The Not People BY B. ELWIN SHERMAN

Ruby is a seventy-year-old woman who has lived with PD for the last seven years. Together with her husband of half a century she traveled the world, lived through lean and prosperous times, and raised a loving, successful daughter. She has a passion for all things floral, painting, cooking, country living, and is quick to embrace the counterpoints of beauty that come from both rainy and sunny days. She measures her quality of life by what is gained, not lost.

PD changed all of that for Ruby, by turning the most commonplace of tasks into near insurmountable challenges.

She now struggles with and often can't do the simplest things: water her houseplants, write letters, read, or just get from bed to bathroom without fear of the very real risk of falling.

Ruby's PD also produced what has become her life's greatest obstacle: what she calls "The Not People." They are hallucinated human characters who have moved into her daily life. They live only in her mind. But, they also present as real to her in her living space as this sentence does to you in yours.

I've been Ruby's caregiver for some time, and we recently sat together and

talked openly about The Not People. She agreed to let me share them with you:

Where did you first see The Not People?

One day I looked outside and there they were: old soldiers coming down the hill. As I watched them march by, I saw a young couple embracing in the grass by the driveway. They moved in closer and closer, and small primitive structures started to appear along the edge of the lawn. I don't know what they were, but they were flat, full of color, and had limited lines.

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

The Parkinson's Center is busier than ever! We held several well-received educational events in 2015:

- Parkinson's Q&A Sessions in April and November at DHMC, featuring our Movement Disorders Team (Drs. Bernat, Coffey, Feldman and Lee),
- "Personalizing Parkinson's" in June at DHMC, with speakers Dr. Mary Feldman Attorney Renee Harvey, and psychologists Bonnie Irwin and Barry Waterson,
- "Moving Forward with Parkinson's" in September at Attitash, with presentations by Dr. Jim Boyd, Parminder Padgett, PT and Sonja Hakala, and
- "Debunking Ten Myths that May Sabotage Treatment of Parkinson's Disease" in October in Portsmouth; this was a special presentation by Dr. J. Eric Ahlskog for our seacoast Parkinson's support groups.

The Parkinson's Center is located within the DHMC Aging Resource Center. Here, I work with a team dedicated to providing outreach, education, resources and support to the community. I hope that you will visit us sometime!

Best wishes,

Diane

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That sounds like a painter describing her art.

I don't know how else to say it. You know how I can't always finish things. The words I want don't come.

Did you talk to anyone about what you saw?

I was afraid to. I thought my husband would think I was crazy, and The Not People made me feel like the only way I could maintain some privacy was to keep this all to myself. Sometimes I still feel like that.

Are you seeing any of The Not People now in this room?

Not now, but in the jade plant over there—the lady who sometimes IS the face in that jade plant when I come in here—one time I decided to talk with her, try to be kind to her, and then maybe she would talk to me and tell me where she was from and why she wouldn't leave the room. I hoped that good will would prevail. I know that it's a strange way of communicating, but now when I enter the room and wiggle my fingers in her direction, her face perks up a bit. She acknowledges me with her funny eyes.

Do The Not People ever talk to you?

No. Never. When it first began, there wasn't any speech, and there still isn't. I've also noticed that their complexions have changed. A lot of them have grown older with me.

But, you talk to them?

Conversations are always one-way, with me doing the talking, asking them not to cause problems or to leave the house, but they never speak to me. There's a woman who goes through my closet.

When I see her in there she will glance at me and I say: "You get out of here, now!" but she just turns back to what she was doing, messing up my clothes.

When and how do The Not People go away? Do they just vanish?

No, it's not like that. They'll just not be there the next time I look in that space. I did look outside and see a big bird once in flight go "phhht!" and disappear, but living out here where we live, that could've been real!

Are there recurring characters? Do you always see the same Not People?

Not really the same, but similar, except for one woman with black hair. I see her in the morning in bed with my husband, but only when I'm up and out of bed looking at him sleeping. When we're in bed together, there may be big lumps that look like a body between us, and my eyes see them as being those of a body, but when I pull down the sheet that covers her, there's nothing there, or there's a sleeping child, or just the head of a child.

Do you ever feel frightened or threatened by The Not People?

There was some fear in the beginning, but as time went by the fear went away. Now, they can be annoying, even entertaining, but not so scary, and I actually had one doctor tell me "When all else fails, just try to have fun with them."

There's a woman who puts a lampshade on her head, not for a joke; she just wears it like a hat. There's another woman I call "Mrs. Square Corners." She has square legs, square arms, and

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a square head. She will stare at me and I ask her "Why are you doing this?" She just looks away. That's always the same. When I come into the living room or look outside, there'll be a group of people of all ages, girls with long dresses and long hair, men in formal wear, and they will look at me and ignore me at the same time. Sometimes they're all holding lit candles, and it looks like some kind of religious service.

There are Not People who stretch their bodies out along the fence like they're long split rails. Others come to dance in the hallway. There are some very pretty young women, very talented. Once in our bedroom, a little girl kept opening the door, a little at a time, until she was all there and started to do a ballet dance in a beautiful costume.

Maybe that doctor was right, especially since I seem to be stuck with them, but I look at it a little differently. I see all this as a gift. At this point in my life, I don't have much of anything else to give away, so I give these. I first thought that The Not People had to be make-believe, but as time has passed, they've settled in to accept their place in our home.

Now you're talking about them like they're real.

They ARE real... to me... but when I talk to them and they don't respond, then I know they're not really there, or when you or my husband or anyone tells me that they're not seeing what I'm seeing, it helps me to tell the difference and I feel a little less crazy. I know it's caused problems between my mother, my father and me. It's like that. Yes, I know they're both long-dead, but I still call out to them. That's when I can get very confused.

Sometimes you have different kinds of visions, what we've come to call your "illuminations." That's when I see a birdhouse and you see a man in a holey grey sweater.

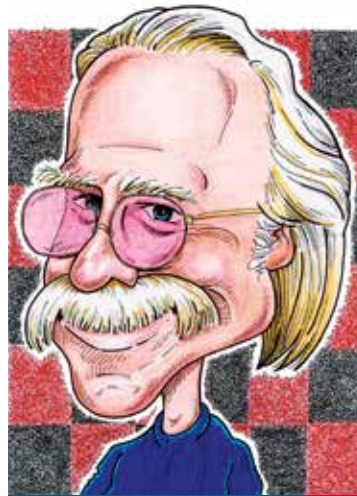
You mean when we both agree that SOMETHING is there, just not about what it is?

Right.

Those can't hold a candle to The Not People.

If The Not People were here right now, what would you say to them?

Ha! They're probably off somewhere busy preparing for their upcoming performances! I'd tell them: "Hats off to those who believe." ●



B. Elwin Sherman is an author, eldercare/hospice nurse and Senior Wire News Service syndicated columnist. You may contact him via his website at Witbones.com.



ANNOUNCEMENTS

Find education, support and camaraderie in the Parkinson's support groups that meet in the following locations:

NEW HAMPSHIRE:

- Brentwood
- Concord
- Conway
- Derry
- Hanover/Lebanon
- Keene
- Manchester
- New London
- Peterborough
- Plymouth (NEW!)
- Rochester
- Wolfeboro

VERMONT:

- Barre/Montpelier
- Brattleboro
- Bristol
- Burlington
- St. Albans
- St. Johnsbury

Please contact the Parkinson's Center for more information!



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“MR. G GOES TO THE HOSPITAL:” A STORY OF GULASH, GRIT, AND GRATITUDE

BY JOHN M. GULASH, III (WITH DIANE L. SHERMAN)

“Hi, my name is John Gulash. I have Parkinson’s disease and this is my story.”

JOHAN GULASH was born on January 26, 1962. Medical problems dogged him since infancy, when he required gastrointestinal surgery. Childhood surgeries left him in knee braces and leg supports for life. “On I went with my weak legs and a song in my heart.” John displayed grit even as a child.

At age 32, John began to experience “weird stuff.” He was working at JCPenney® when he noticed a left arm tremor. His legs shook, too, especially in doorways; uncontrolled movements caused him to kick a co-worker. He would frequently freeze, unable to move. Walking up and down ramps was like hiking Mt. Everest, and he sweated so much that he brought an extra shirt to work each day. He noticed difficulties when behind the wheel of his car: “Thank God I was never in an accident before I stopped driving!”

“I didn’t know what was happening to me... I was really scared.” A neurologist diagnosed John with “parkinsonism,” a word he’d never heard before, and prescribed Sinemet. John’s dad encouraged him to “just keep moving, boy!” And so John did. In 2000, he had Deep Brain Stimulation (DBS) surgery. He advises others: “Give yourself lots of time to get used to DBS and to changes in PD drugs you are taking.”

Now in his 50s, John has experienced more than his share of both chronic

and acute medical difficulties. As an adult, his resilience has allowed him to deal with a blood clotting disorder, chronic and nearly unbearable leg pain, vascular problems and infections, and vertigo. All in addition to Parkinson’s.

John is deeply appreciative of those who have treated him with compassion. He wrote that the hardest part of his PD diagnosis was telling his parents, who’d already been through so much with his early health problems. He has poignant memories of his mother, who put her teaching career on hold to stay with him during childhood hospitalizations. She wheeled him to the craft room to make Christmas ornaments from yarn and raw macaroni. She comforted him when Maria, fellow hospital resident, best buddy and daily playmate, died at just five years old.

Of former co-workers, he wrote, “I will always be glad I was at JCPenney. They were so very good to me. When I really started to show signs of Parkinson’s, they let me do as I could. If I had to leave, ‘Okay, Jonni, go home.’ When I had to quit, that was my choice, too.”

And he is grateful for friendships. John was scheduled for an early morning medical procedure but wasn’t taken to the operating room until 7 pm. “Without my PD meds, I was a brick by 10 am: I could not move a muscle... Thank God for a friend

who stayed with me to be my head and my hands, moving me as one would a puppet.”

After decades of dealing with his health issues, John realized that he could no longer care for himself. He moved to a nursing home. “It took a while to adjust to not being on my own, but in time I became part of a community of people that were in the same boat.”

He now lives at Loretto Home in Rutland, VT, which provides him space, privacy and a great room. He describes Loretto’s leadership and management as “fantastic...wonderfully helpful.” The nurses are “the finest, most competent and totally professional... They never forget that they are dealing with people with different needs.” The cooks prepare tasty, beautifully-presented food, and maintenance and housekeeping are also “top shelf.” “The staff will go a long way to help you... I feel so comfortable, I hope I can stay here for the rest of my days.”

“By telling my story, I want to help you to understand that **medical problems don’t condemn you to a sheltered life.** Get up and get out in the world, meet people, do something you always wanted to do. Just remember you can do anything you set your mind to do. So what if it takes you longer to get there... Every day above ground is a good day. And if it ain’t broke, don’t fix it!” ●



Get Up and Go???

BY GAY PALAZZO

It's 8:03 in the morning.

I pop a Sinemet pill into my mouth. I have an hour before I can have breakfast so I check my computer for messages. The day stretches ahead and the phone rings. It is a friend who says "I am going to exercise class, want me to pick you up?" I respond that I am all set and will see her there. I eat breakfast and turn to my book "Cleopatra". The next time I look up I am clearly not going to make class.

The following week, I missed class as well. I had a legitimate excuse, but after that, it was all downhill. I found reasons not to go to many activities that I had always looked forward to.

I cancelled exercising with my personal trainer and I called in sick for my usual shifts at the Food Pantry. I kept saying that it was summer and I'd go hiking, biking, etc., but I didn't do those either. Even gentle nudging by my husband didn't spur me to action. And the tennis racket that I bought at the local thrift shop has gone unused.

You might have noted that I got myself to the thrift shop with no problems. And I just walked to the refrigerator for a snack too.

What to do. How can I get out of this funk? I keep thinking I need one of those fancy wrist things that tells me how many steps I have taken, etc., but I know that I haven't taken enough steps and a wrist thing isn't going to make me change.

My membership at the gym was going unused and guilt is a powerful motivator. When I had finally run out of excuses, I headed off to an aerobics class. There, several in the class greeted me with a "welcome back" and the pre-class chatter filled me in on everyone's summer trips and family happenings. I looked for my usual spot in the middle of the second row and slipped right in. The instructor welcomed us all to class, and the warm up music was "There's a hero." The date



was Sept 11th and she told us that it was the anniversary of her 14th year at the gym and also the anniversary of the World Trade Center collapse. While we warmed up, we shared brief stories of what we were doing that long sad day.

After class, I approached the instructor. She told me that I am not alone and many others that she usually sees in class are also "no shows" in the summer, near a holiday, etc. I left the gym feeling glad that I had gone, both for the exercise and the comradeship.

I have a personal trainer to help me work on specific "deficiencies." She is quite vigilant and showed me no mercy. She looked at me with her dark brown eyes, and nodded as she said "I have you in my schedule for Monday at noon." I know I will be there.

The Food Pantry called to confirm that I will be at my shift on Thursday. When I arrive, I get a hardy hello from

my shift mates. I feel welcomed and am glad to be back. The shelves were empty that morning, and we filled them with deliveries from area produce companies, grocery stores, bakeries, and an organization called "Willing Hands."

When I leave later in the day, I am once again humbled by the generosity of those in our community and by the gratitude of the shoppers who range from veterans to grandmothers who are feeding three generations of families.

Gradually, I am getting back in the groove. This is made easier by the support I get from those around me. I remind myself that I can help others as well. Although there is no quick, easy way, the road points ahead and together we take one step and then another.

There are many reasons to "get up and go" and they are all good. Oops, here I go again. It is late and I am not dressed for class. Got to run! ●



The Parkinson's Research Group at Dartmouth-Hitchcock/Geisel School of Medicine at Dartmouth: Left to right: Matthew Havrda, PhD; Stephen Lee, MD, PhD; David Coffey, MD; Pauline LeBlanc, Research Coordinator; Mary Feldman, DO. Absent from photo: Georgia Olsen, LPN; Charlotte Jeffreys, Research Coordinator

A History of Parkinson's Research at Dartmouth-Hitchcock

The mission of Dartmouth-Hitchcock is “to advance health through research, education, clinical practice and community partnerships...” Here, we focus on the research aspect of that mission.

THE DEPARTMENT of Neurology's clinical research program was founded in 1988 by Drs. David Coffey, Lawrence Jenkyn and Thomas Ward. Parkinson's research at DHMC began in 2003, when Dr. Coffey was asked to be Principal Investigator at DHMC for a multi-site Parkinson's study.

Potential study participants are identified by their doctors and through websites (dartmouth-hitchcock.org/

cto.foxtrialfinder.michaeljfox.org; ClinicalTrials.gov), support groups, the Parkinson's Center, and NET-PD (NIH Exploratory Trials in Parkinson's Disease), which is funded by the National Institute of Neurological Disorders and Stroke (NINDS) and seeks to find drugs to slow the progression of PD in trials. Our specialists also participate in the Parkinson Study Group (PSG), which is a network of experienced physicians and coordinators dedicated to Parkinson's research. Research by the PSG, in collaboration with pharmaceutical companies and the NIH, has brought numerous PD drugs to the market, including entacapone, pramipexole, rasagiline and rotigotine.

Despite this extensive outreach, finding

sufficient numbers of research participants remains a major stumbling block in carrying out clinical studies: Four or five patients must be pre-screened to enroll just one patient who meets inclusion/exclusion criteria for a particular study! Up to 70% of PD research programs are delayed due to limited participation, so MANY MORE volunteers are needed if new treatments for PD are to be identified. Please contact the Parkinson's Center if you are interested in volunteering for a clinical research project.

Our research team has grown to include several principal investigators and research coordinators (see photo) with ongoing projects in both clinical and laboratory-based studies.

A Timeline of Parkinson's Research at DHMC

The clinical trials listed here are multicenter, double-blind, placebo-controlled studies unless otherwise indicated, and results are based on averaged scores of all participants in a study.



Research study	Scientific background	Results
<p>2003-2005 Safety and tolerability of minocycline and creatine in patients with early untreated PD: Participants received placebo and minocycline or creatine, or placebo alone. SPONSOR: NINDS/NET-PD; DR. COFFEY/POLLY LEBLANC</p>	<p>Minocycline is an antibiotic and anti-inflammatory drug with antioxidant properties. Creatine occurs naturally in the body and is involved in energy production in muscle, brain and nerve cells. Both compounds demonstrated neuroprotective properties in animal models of PD.</p>	<p>Both compounds were determined to be safe and well-tolerated. Further study is required to determine efficacy in slowing PD progression. Published: NET-PD Investigators, Neurology (2006), Vol. 66: p. 664-671</p>
<p>2004-2005 Safety and tolerability of coenzyme Q10 (CoQ10) and GPI-1485 in patients with early untreated PD. Participants received combinations of placebo with CoQ10 or GPI-1485, or placebo alone. SPONSOR: NINDS/NET-PD; DR. COFFEY/POLLY LEBLANC</p>	<p>CoQ10 is an antioxidant that occurs naturally in the body. GPI-1485 is a drug that binds to a class of compounds found in the brain called neuroimmunophilins. Both compounds demonstrated neuroprotective properties in animal models of PD.</p>	<p>Both compounds were found to be safe and well-tolerated. Further study is required to determine efficacy in slowing PD progression. Published: NET-PD Investigators, Neurology (2007), Vol. 68: p.20-28</p>
<p>2004-2006 DNA Repository for Patients with PD: Samples of blood were collected from people with PD and non-parkinson subjects and stored at the NINDS for future studies. SPONSOR: NINDS; DR. COFFEY/POLLY LEBLANC</p>		
<p>2004-2007 (Four studies): The safety and efficacy of istradefylline in treating PD patients with motor fluctuations. The studies were either, a) double-blind and randomized (participant received placebo or istradefylline), or b) "open label" (participant knowingly received istradefylline rather than placebo). SPONSOR: KYOWA PHARMACEUTICAL; DR. COFFEY/POLLY LEBLANC</p>	<p>Istradefylline blocks adenosine A2A receptors in the brain stem. It specifically targets the part of the brain affected by PD.</p>	<p>Istradefylline was found to be safe. It reduced "off time" in people on levodopa with motor fluctuations but may increase dyskinesias. This drug was approved in 2013 in Japan but has not received United States FDA approval. Published: PA Lewitt et al, Ann Neurol (2008) Vol. 63: p. 295-302; Mizuno et al, Movement Disorders (2013), Vol. 28: p. 1138-1141</p>
<p>2004-2009 (Two Studies): Evaluating Altoprane with respect to a) safety in patients with tremor, and b) efficacy in differentiating between whether tremor caused by PD or other syndrome. Participants received an injection of altoprane and underwent SPECT brain imaging. SPONSOR: BOSTON LIFE SCIENCES, INC/ALSERES PHARMACEUTICALS, INC; DR. COFFEY/POLLY LEBLANC WITH DR. ALAN SIEGEL, DIAGNOSTIC RADIOLOGY, DHMC</p>	<p>Altoprane is a molecular imaging agent that binds to dopamine transporter (DAT) protein on dopamine-producing neurons in the brain, making the transporters visible during SPECT imaging. DAT protein is expected to be reduced in PD patients relative to controls or patients with tremor unrelated to PD.</p>	<p>Altoprane binds dopamine transporters quickly and selectively. It may be useful in the differentiating between PD and other causes of tremor, and in early diagnosis of PD. Results of these studies have not yet been published.</p>

Research study	Scientific background	Results
<p>2006–2008 The safety, tolerability and efficacy of E2007 in levodopa-treated PD patients with motor fluctuations. Participants received E2007 or placebo. SPONSOR: EISAI MEDICAL RESEARCH, INC; DR. COFFEY/POLLY LEBLANC</p>	<p>E2007 is a drug that blocks the action of glutamate, a neurotransmitter. E2007 improved the effect of levodopa in animal models.</p>	<p>E2007 was safe and well-tolerated but ineffective in reducing motor fluctuations in PD patients treated with levodopa. Published: A. Lees et al., 2012 <i>Movement Disorders</i>, Vol. 27: 284-288</p>
<p>2006–2008 The safety and efficacy of pramipexole (Mirapex®) in early PD patients: Participants received various dosages and administration schedules of pramipexole or placebo, and effects on PD motor symptoms, mood, thinking, impulse control, fatigue, daytime sleepiness and night time sleep were monitored. SPONSOR: PSG/BOEHRINGER INGELHEIM; DR. COFFEY/POLLY LEBLANC</p>	<p>Pramipexole is a dopamine agonist that acts in place of dopamine</p>	<p>Pramipexole was safe and effective in treating motor symptoms. Participants were not selected for nonmotor symptoms so the following observations are inconclusive: Quality-of-Life and Activity of Daily Living scores improved. Depression and nighttime sleep unaffected. Daytime sleepiness increased. Published: PSG PramiBID Investigators, <i>Movement Disorders</i> (2011), Vol 26: p. 37-44</p>
<p>2006–2013 A long-term study of the efficacy of creatine in slowing PD progression. Participants received either creatine or placebo, in addition to their PD medications, for several years. SPONSOR: NINDS/NET-PD; DR. COFFEY/ DR. LEE/POLLY LEBLANC</p>	<p>Creatine was safe and well-tolerated in earlier clinical trials, and demonstrated neuroprotection in PD animal models. (See 2003-2005 study, above.) This study investigated its effectiveness in slowing progression in PD patients.</p>	<p>Creatine did not slow PD progression in participants taking creatine for at least five years. Published: NET-PD LS-1 Investigators, <i>JAMA</i> (2015), Vol. 313: p. 584-593</p>
<p>2011–2014 The safety, tolerability and efficacy of pioglitazone in slowing disease progression in early PD patients treated with rasagiline or selegiline. Participants received pioglitazone or placebo. SPONSOR: NINDS/MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH; DR. COFFEY/ DR. LEE/DR. SHITAL SHAH/POLLY LEBLANC</p>	<p>Pioglitazone binds PPAR-γ, a receptor that is abundant in neurons of the substantia nigra and central nervous system immune cells. Pioglitazone prevented or slowed neurodegeneration and development of motor symptoms in animal models of PD.</p>	<p>Pioglitazone was ineffective in slowing PD progression in study participants. Published: NET-PD FS-ZONE Investigators, <i>Lancet Neurology</i> (2015), Vol. 8: p. 795-803</p>
<p>2011–2012 Handwriting in PD patients using electromyography (EMG) and electroencephalography (EEG). SPONSOR: NORCONNECT; DR. JAMES LEITER (DHMC PHYSIOLOGY)/DR. LEE/POLLY LEBLANC</p>	<p>Small handwriting (micrographia) is often an early sign of PD. This study analyzed EMG and EEG activities during handwriting, which may provide a tool to diagnose PD earlier.</p>	<p>Neural signals obtained from muscle and brain electrical activity during handwriting may serve as a diagnostic tool. Published: Time-dependent statistical and correlation properties of neural signals during handwriting. Rupasov et al. <i>PLoS One</i>, 2012 Sept 11. PMID 22984455</p>
<p>2015–Present The effect of visual adaptation on gait problems. Participants train while wearing goggles with different types of lenses. SPONSOR: THE HITCHCOCK FOUNDATION; DR. LEE/ DR. JANET BULTITUDE/POLLY LEBLANC/CHARLOTTE JEFFREYS</p>	<p>Gait freezing can be difficult to treat. This study asks whether the visual adaption, a method well studied in rehabilitation medicine, when applied to PD patients, can improve gait speed and decreased gait freezing.</p>	<p>This study is in progress and is currently recruiting participants with PD and gait freezing. Preliminary studies indicated that visual adaptation improves gait initiation in PD. Preliminary studies by Dr. Bultitude have been published: <i>JH Bultitude et al., Front Neurol</i> 2012 Sep 28;3:132 PMID 23060652</p>
<p>2015–Present The efficacy of isradipine in slowing disease progression in early PD patients. Participants receive either isradipine or placebo. SPONSOR: NINDS/MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH; DR. LEE/DR. FELDMAN/POLLY LEBLANC</p>	<p>Long-term use of isradipine, a calcium-channel blocker approved for treatment of high blood pressure, is associated with reduced risk of PD. Isradipine was neuroprotective in cell cultures and animal models of PD. Isradipine is safe and well-tolerated.</p>	

Research study	Scientific background	Results
<p>2015–Present Mechanisms of rotenone-induced neuroinflammation and Parkinsonism in aging mice. (Laboratory research) SPONSOR: NIH/NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES (NIEHS); DR. HAVRDA</p>	<p>We have identified novel cellular mechanisms of progressive neuroinflammation in the brains of mice exposed to low doses of rotenone, a pesticide that increases the risk of PD in agricultural workers. We will characterize these mechanisms during the earliest stages of PD in this animal model as a step towards developing preventive and protective therapies.</p>	
<p>2015–Present Neuroinflammation in PD: The NLRP3 inflammasome. (Laboratory research) SPONSOR: MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH; DR. HAVRDA/DR. LEE/DR. FELDMAN</p>	<p>Neuroinflammation occurs in the brains of animal models of PD and is observed in PD patients. Neuroinflammation is an immune response associated with nerve cell damage. "Inflammasomes" are protein complexes involved in our immune responses that may have a role in PD-associated neuroinflammation. Using brain tissue donated post-mortem by PD patients, this study will seek to determine if the NLRP3 inflammasome is activated in PD towards identifying new biologic markers of PD progression that may be used to develop new disease-modifying strategies.</p>	

Clinical research requires great teamwork.

“Principal Investigators” and “Research Coordinators:”
 What are their roles?



THE PRINCIPAL INVESTIGATOR (PI)

- Is the lead researcher for a study
- Is a medical doctor or nurse practitioner
- Assumes full responsibility for staff supervision and all technical, administrative, regulatory and financial aspects of the project
- Works with the Dartmouth’s Committee for the Protection of Human Subjects (CPHS) to ensure the safety of study participants
- Receives support from the Office of Sponsored Projects, investigative pharmacies and labs, and Research Coordinators

THE RESEARCH COORDINATOR

- Serves as liaison between the funding sponsor, PI, participants and CPHS
- Submits regulatory documents, revisions and renewals to the CPHS
- Advertises for, screens, consent, enrolls, and randomizes participants
- Schedules and conducts participant study visits and tests
- Tracks and documents adverse events
- Compiles source documents
- Fills out required logs and case report forms
- Follows GFP (Good Clinical Practices) and ICH (International Conference on Harmonization) guidelines for research on human subjects
- Communicates effectively with the study team to address queries
- Attends investigator meetings and coordinates monitoring visits

New Programs for Reducing Your



Falls are the leading cause of injury among older adults, with one out of three experiencing a fall each year.

Not all falls cause serious injuries, but many falls are serious enough to cause injuries that can have long-term health impacts. Risk of falling is higher for individuals with Parkinson's disease. The motor symptoms of PD, including changes in posture, gait, and balance, result in a higher risk of falling. Non-motor symptoms also play a role. These include rapid blood pressure changes that cause dizziness, fatigue from sleep issues, and changes in executive functions that can cause distraction.

Many people who fall once (or more) become afraid of falling. This fear of falling is often associated with a reduction in activity or exercise, as individuals restrict their activities to avoid falling. But maintaining

activities and getting exercise is critical for individuals with PD! Reducing activity can also lead to becoming more socially isolated, possibly leading to depression and less mental stimulation.

However, there are measures that individuals and family members can take to reduce the risk of falling. Changes can be made in the home, such as installing grab bars, removing rugs, improving lighting, and making sure footwear is in good condition. Individuals should also have periodic medication reviews by their health care team and pharmacist to ensure that drug interactions are not needlessly increasing the risk of a fall. And patients should be honest with their health care provider about their consumption of alcohol and non-prescription substances or supplements, as these can complicate drug interactions.

There are also programs that can help reduce the risk of a fall. Dartmouth's Centers for Health and

Aging has received a federal grant from the Administration for Community Living to increase the number of these programs that are available, and to make people more aware of the benefits of joining one of these programs. Two falls prevention programs that have been extensively tested and found to be effective were selected for this effort.

Tai Ji Quan: Moving for Better Balance® (tjqmbb.org) was developed by Fuzhong Li, PhD, at Oregon Research Institute. This program is based on Tai Ji Quan, a martial art, but has been specially adapted to increase or help maintain balance, gait, and mobility. While someone with very serious mobility issues may not be able to complete the exercises, individuals who sometimes need walking assistance (such as a cane or walker user), people with balance disorders, muscle weakness, and abnormal gait can all benefit. In community-dwelling individuals, this program has been shown to reduce the

Risk of Falls!

By Lora Wise, MPA, Program Leader,
Geriatric Education Center, Dartmouth
Centers for Health and Aging



number of falls by 55%. In individuals with Parkinson's disease, a 67% reduction in falls risk has been demonstrated. Tai Ji Quan: Moving for Better Balance® is most effective when participants take 2-3 one hour classes each week, for a minimum of 24 weeks. Classes consist of sitting, standing, and stepping exercises, led by an instructor specifically trained in this program. Typically no more than 10 people participate in a class.

Another program, Matter of Balance (mainehealth.org/mob), helps reduce the fear of falling. This program will benefit individuals who are ambulatory and able to solve problems but are concerned about falls, have fallen in the past, restrict activities due to a fear of falling, or want to improve flexibility, balance, and strength. This class, which typically meets for two hours per week for eight weeks, is predominantly discussion based and focuses on practical solutions to falls risk factors. There are some light exercises for strength and balance. ●

These classes are currently offered in a few locations in our region, but this federal program is allowing us to train and support many more instructors at sites throughout the state.

New classes will open in the winter and continue throughout the following months. We hope that as many people as possible can benefit from these programs! Individuals who would like to be placed on a list for referral as classes open should contact the Aging Resource Center at:

agingcenter@hitchcock.org
or **603.653.3460**

Please give us your full name, contact information (email and phone) and where you live so we can match you to programs as they become available.

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 Information and Referral Center at Dartmouth-Hitchcock.

TO DONATE BY CHECK,
Please make check payable to:
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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 health care provider.



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Attention: Diane L. Sherman

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