

# Binter Center Newsletter

## Summer 2023

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### TOP STORIES: "HYPE VS HELP"



### A Message from the Binter Center

In this issue of the Binter Center newsletter, we focus our attention on "Hype vs Help". Whether we conduct research, provide clinical care, or are personally affected by a movement disorder, we all share the same goals of minimizing symptoms, improving quality of life, reducing disease progression, or preventing development altogether. Looking forward and maintaining hope (a desire accompanied by expectation of or belief in fulfillment) for newer and better treatments is essential. Therefore, keeping the public aware of ongoing advances in understanding these conditions and the treatments on the horizon is paramount. Balancing that knowledge sharing while being cautious to avoid the risk of creating hype (exaggerating the importance or benefits) can be challenging. The hype surrounding any particular treatment option should be met with a reasonable level of skepticism. Hyped-up treatments can appeal to the hopes and fears of patients and their families. After national news stories or research announcements, clinicians often field questions about when these treatments will be accessible and why we are not offering /recommending/offering them now. Hype vs Help articles in this edition are written from the first-hand experience and literature review of the physician author. Our goal is to provide an objective and balanced summary of the scientific evidence available on each of these topics. We encourage you to reach out should you have any further questions.

In Solidarity,

Dr. James T. Boyd, Binter Center Director

Brandolyn Bradley, Binter Center Program Coordinator

## Staff Spotlight: Binter Center Staff Nurse Jennifer Erwin!



The Binter Center is excited to introduce to you Jennifer Erwin has been a dedicated nurse with the University of Vermont Medical Center for 25 years, starting with in-patient rehab in 1998; 11 of those years have been with the Binter Center. Her interest in Neurology and Movement Disorders started early in her life. Her ability to be a floor nurse made her an excellent addition to the Neurology department, bonding quickly with the other nurses in the department. She found she connected well with other staff and the patients being served and feels the sense of family the Binter Center fosters. She was born in Burlington, VT, and has lived in Winooski for over 20 years where she has raised two beautiful children. She's been involved with Girl Scouts as a troop leader for 23 years, with both of her children being involved. She enjoys camping and hiking and loves summers in Vermont. She also enjoys crocheting and going to Renaissance fairs. Her ultimate bucket list is to go to a Renaissance fair in every state in which they're held. She recently finished her Bachelor's Degree from Western Governor's University. Her dedication to our patients keeps her grounded and fuels her passion to create the best patient experience possible and her dreams of creating programs that address patient needs.



### Hype vs Help: Beans, beans, the magical fruit... in Parkinson's?

By: Lisa Deuel, MD

*Mucuna pruriens* (MP; also called the velvet bean, kapikacchu) is a legume native to Africa and tropical Asia, commonly used in traditional India (Ayurvedic) medicine for a number of purposes due to possible effects as a dopamine booster, aphrodisiac, antioxidant, and more. It can also serve as a food supplement when cooked, as it is rich in protein but can be harmful if eaten raw. According to studies, the seeds from this plant include up to 6% levodopa (l-dopa), which can be extracted from the plant and used for medicinal purposes

In animal studies, MP shows similar improvements in mobility compared to equivalent doses of synthetic l-dopa, and may also protect nerve cells from dying. In humans, there have been several studies since the 1970's that show an anti-Parkinson's effect, so we know that this works to treat PD symptoms. There have also been a few small studies that have compared MP to synthetic l-dopa, and overall this looks like it works just as well and may even start working faster. It may also be less likely to cause those involuntary, wiggly movements we call "dyskinesia" and some people find they have fewer side effects. Because these studies have all been so small, it is hard to know if this would work like this for everyone.

So if you take MP, what is the correct dosage? This is always tough to say, because MP does not include the carbidopa which helps it travel from your blood to your brain. As a result, you need a lot more MP to get the same results from l-dopa. For example, in some studies, people were given up to 30 *grams* of MP compared with 200 *milligrams* (a 150-fold difference). If you buy MP supplements, you can calculate the amount of l-dopa that is contained in each dose by multiplying the total dose by the percent l-dopa, but it won't tell you how much actually makes it to the dopamine cells in your brain.

For example: **800 mg** of MP with **15 %** l-dopa = **120mg total of l-dopa**, but not all of the l-dopa crosses into the brain.

## Beans! Cont.



<b>Supplement Facts</b>		
Serving Size: 2 Vegetarian Capsules		
Servings per Container: 45		
	Amount Per Serving	% Daily Value
Velvet Bean Extract ( <i>Mucuna pruriens</i> ) (Seed) (min. 15% L-Dopa, naturally occurring)	800 mg	*
L-Dopa	120 mg	*
*Daily value not established.		

There are no specific downsides to MP extract, however anything that is over-the-counter will have to be paid for out of pocket, and that can really add up depending on how much you are taking.

There are some other beans that we eat in the U.S. that have l-dopa as well – this includes fava beans (AKA broad beans) and soybeans – but they have a much smaller percentage of l-dopa. So unfortunately, eating a can of your favorite beans is not likely to have much of an impact on your PD symptoms.



### Hype vs Help:

## High Dose Thiamine as a Treatment for PD? More Information is Needed.

By: Joseph Gross, MD, Movement Disorders Fellow

Have you ever encountered claims on the internet or elsewhere that vitamin B1, also known as thiamine, can be used to treat Parkinson's Disease?

Thiamine (vitamin B), is an essential micronutrient for humans that is found in various food sources including whole grains, legumes, and some meats and fish. Risk factors for deficiency in the U.S. include chronic alcohol use, diabetes, HIV, gastrointestinal disease and use of some diuretics.

An association has been found between Parkinson's Disease and low levels of thiamine in the blood. However, as you likely know, an association between two findings does not necessarily imply a causal relationship. While PD patients are understandably eager and hopeful for new treatments, the role that thiamine may play in the treatment of Parkinson's has been investigated in several studies, without definitive conclusions.

There have been some limited studies and theorizing about how thiamine deficiency may play a role in the pathogenesis of PD. Most of these theories revolve around that many enzymes in the brain neurons depend on thiamine for proper functioning. For example, the study "An open-label pilot study with high-dose thiamine in Parkinson Disease" published in *Neural Regeneration Research* in 2016 reported improvement in 10 patients with Parkinson's who received 100 mg of thiamine which was injected intramuscularly two times per week.

## High Dose Thiamine Cont.

Although the authors report improvement in both motor and non-motor symptoms of Parkinson's Disease, it should be noted that this was a very small study and that there was no placebo group. Patients with Parkinson's who are being told that they are receiving treatment, even if this treatment is in fact an inactive substance, or placebo, can often show improvement in their exam due to the power of suggestion. Additionally, many of the patients in this study either increased the dosage of levodopa that they were already taking or, if they weren't already taking levodopa, started taking it in the course of the study. This raises the possibility that their symptoms improved largely from the levodopa, which is the mainstay of therapy for Parkinson's.

Intramuscular injections of high-dose thiamine is not currently a treatment for Parkinson's that has been put into standard practice, and the take-home message from those studies that have been done is that more information is needed.



## Hype vs Help: Vibrating Gloves?!

By: James Boyd, MD

Featured on the Today Show in early 2023, the use of vibrating gloves as a treatment for Parkinson's disease (PD) has generated excitement among the medical community and the general public alike. Over a century ago, famous French neurologist Jean-Martin Charcot described improvement in Parkinson's disease movement symptoms from the vibration of long-distance jostling rides on carriages and locomotives. Charcot later developed a vibrating chair and reported it to provide temporary PD symptom relief. More recently, Peter Tass, MD, Ph.D., and his research team at Stanford University reapproached this question with more rigorous and refined scientific investigations and found some interesting preliminary results. Testing began in an open-label fashion (knowing they were receiving a treatment) on 8 participants, evaluating the effects of stimulation to the fingertips for several hours a day over 3-6 months. They were able to show normalizing effects on the abnormally rhythmic brain waves (measured through the scalp – aka EEG or electroencephalography) created by PD. These early findings provided evidence that finger vibration could impact brain function. In addition, some participants observed improvements in PD motor symptoms and a reduction in total PD medicines needed.

It is important to note that this is only the beginning of research into the use of vibrating gloves for Parkinson's disease. The level of evidence thus far justifies continued discussion, and further research will be crucial in establishing efficacy and safety more definitively.

One ongoing study aims to evaluate the effectiveness of vibrating gloves in a larger sample size of Parkinson's patients, with 30 participants enrolled in the trial. This study will also examine the effects of varying vibration frequencies and whether the duration and frequency of treatment impact clinical outcomes. Another study is investigating the use of vibrating gloves in combination with other therapies, such as medication and physical therapy, to determine whether the combination of treatments could lead to greater improvements in Parkinson's symptoms than any one treatment alone.

If successful, the use of vibrating gloves could provide a non-medication, non-invasive, and affordable option for Parkinson's patients to manage their symptoms and improve their quality of life. Despite the tremendous hype generated by national news coverage, there is plenty of reason to find hope in this innovative approach to treating Parkinson's disease.



## Hype vs Help: Focused Ultrasound... For ET & PD?

By: Deepak Gupta, MD

Tremors, especially hand tremors, can significantly impact an individual's quality of life, affecting their ability to perform daily tasks and enjoy everyday activities. Essential tremor (ET) and Parkinson's disease (PD) are two conditions commonly associated with hand tremors. Several different oral medications are available to treat tremors in ET and PD, however, these medications might not provide enough benefit and / or cause side-effect for a subset of patients with hand tremors in ET or PD. For treatment of such refractory and severe tremor, deep brain stimulation (DBS) has been available for more than two decades as a surgical procedure. Recent advances in technology have paved the way for a new procedural treatment option for tremor, known as focused ultrasound (FUS). In this article, we will review FUS as a treatment strategy for tremor in both ET and PD, and compare it to DBS.

ET is a neurological disorder characterized by action tremor, typically affecting the hands, arms, head, and voice, and not associated with degeneration of brain cells. ET is typically not accompanied by other motor or non-motor symptoms. PD, on the other hand, is a progressive neurological disorder caused by the degeneration of brain cells. Tremors in PD are often accompanied by other motor symptoms, such as stiffness and bradykinesia (slowness of movement), and dream-enactment behavior, constipation, and loss of sense of smell.

Focused ultrasound is an imaging-based technology that uses thermal energy from ultrasound-generated sound waves to target and ablate (destroy) specific tissue deep within the body under guidance of magnetic resonance imaging (MRI). This procedure allows for precise lesioning of the brain tissue without the need for surgical incisions or radiation exposure. During FUS treatment for tremor, patients lie inside an MRI scanner while an ultrasound transducer is placed on the scalp. The transducer emits focused ultrasound waves, which pass harmlessly through the skull and converge at a specific target within the brain. This target is usually the thalamus, a region involved in tremor control. Heat from focused ultrasound creates a lesion in the thalamus, disrupting the abnormal neural activity responsible for tremors.

Multiple clinical studies have demonstrated the efficacy of FUS in reducing tremors associated with both ET and PD. Patients often experience a significant improvement in tremor severity, allowing them to regain control over their movements and enhance their overall quality of life. However, some studies suggest that the effect of FUS may not be durable and patients may require repeat procedures after 1 or 2 years due to fading of the benefit. Although there are no major adverse effects from FUS treatment, some patients may experience temporary or sometimes persistent side effects such as headache, tingling sensations, or balance issues following the procedure. FUS may not be suitable for all patients, as factors such as skull thickness or the presence of certain implants may limit its effectiveness or safety.

### Comparison with Deep Brain Stimulation (DBS):

Deep brain stimulation involves the surgical implantation of electrodes in specific regions of the brain, followed by the delivery of mild electrical pulses which modulate abnormal brain activity for reducing tremor. DBS has been widely used for tremor management in both ET and PD for over 20 years. Table 1\* provides a summary of comparison of FUS with DBS.

\*Table 1 is on the following page



## Focused Ultrasound Cont.



Parameter	Focused Ultrasound (FUS)	Deep Brain Stimulation (DBS)
Procedure	Non-invasive procedure where ultrasound waves are used to create lesions in the brain's target region.	Surgical procedure involving the implantation of electrodes in specific brain structures.
Targeting	Ultrasound waves target a specific brain region, such as the thalamus.	Electrodes are implanted in deep brain structures, such as the thalamus or subthalamic nucleus.
Invasiveness	Relatively non-invasive: although it does not require incisions or electrode implantation, it does entail brain lesioning from heat wave	Relatively invasive: requires surgery for implantation of the electrodes in brain and battery in chest.
Adjustability	Less adjustable after the initial treatment session.	Adjustable stimulation parameters post-implantation.
Efficacy	Demonstrated efficacy in reducing tremors in both Essential Tremor and Parkinson's Disease.	Proven track record of providing long-term tremor in both Essential Tremor and Parkinson's Disease.
Safety	Generally safe with low risk of adverse effects.	Surgical procedure carries risks, such as infection or bleeding.
Recovery Time	Shorter recovery time compared to DBS.	Longer recovery time due to surgical procedure.
Hospital Stay	Usually performed on an outpatient basis.	Requires hospital stay for surgery and post-operative care.
Availability	Availability may be limited to large hospitals only due to high cost of the machine.	Widely available in movement disorders centers.

## Community Events

### World Parkinson's Disease Day 2023!



On Tuesday April 11, 2023 the Binter Center partnered with the Flynn Center for the Arts to celebrate World Parkinson's Disease Day! This special celebration showcased informative and interactive presentations of programs offered to our PD community. Presentations included Tai Chi for People with PD, PushBack at Parkinson's Disease™, PD Mime Therapy, Rocky Steady Boxing, and Movement for Parkinson's w/ Circlesing. The presentations were followed by a flash mob on Church Street in Burlington.

## Community Events Cont.



### Parkinson's Awareness Month Symposium and 2nd Annual Ashok Gupta Memorial Lecture in Parkinsonian Disorders



From left to right: Katherine Chan, Dr. Deepak Gupta, Dr. Michael A. Schwarzschild, Emily Houston, Dr. Lisa Deuel, and Dr. James Boyd,

The Frederick C. Binter Center for Parkinson's Disease and Movement Disorders hosted a Parkinson's Awareness Month Symposium and 2nd Annual Ashok Gupta Memorial Lecture in Parkinsonian Disorders on Friday April 21, 2023 at the Davis Auditorium in the University of Vermont Medical Center and virtually through Zoom.

Topics included Building Resilience in PD, PD and the Gut & Microbiome and included guest speaker Dr. Michael Schwarzschild from Mass General Brigham & Harvard University.

A recording of this year's event can be viewed by clicking [HERE](#). Please note the recording requires a passcode: 84w\$aQPB

### The First Northern Vermont Hike, Check/Done!



Not a dull moment on our inaugural hike at Mount Philo! The early rain on Saturday June 10th was daunting but arrival at the Mount Philo State Park to find the fee waived for Vermont Days was a bonus! Hike leaders, Pam Padgett, Maggie Holt and Kelsey Barklund enjoyed a few minutes waiting in the parking lot for the masses to arrive, and spent that time wisely checking out the seating and entertaining options in the rear of the Padgett VW station wagon (aka, the caRV). We soon realized our sole participant for the hike was going to be Amy Bove...or so we thought. We started out with hiking poles and kerchiefs on hand and headed up the trail.

We braved the rooty portion of the trail taking the occasional break. On one such break, we eyed a spry gentleman wearing white blazing up the trail, only to realize it was John Eisenmann! He had taken a wrong turn and as a result the scenic route to Charlotte via Bristol...you know the one when you miss your turn in Hinesburg? Despite this, he was all smiles and instantly doubled our participant list! It was a win-win. We talked about it all, as you do on a hike, tales of traffic delays, good books, hikes we love. We saw some beautiful mist followed by sunshine and the lake we all know so well. We spied some amazing wildlife, including millipedes, a newt and a scarlet tanager. We ate cookies and muffins. Best of all we smiled a lot, we laughed and we spent time in nature. We will do it again...there is talk of the 2nd Saturday in July...keep your eyes peeled for details. Until then, happy trails!

## PRESS Program

### Parkinson Roadmap for Education and Support Services

The PRESS Program is an 8-week group that provides an opportunity for people with Parkinson's disease and their care partners to meet with others facing a similar experience. The group is for those who have been diagnosed within the last 5 years and focuses on the sharing of coping strategies regarding day-to-day issues related to living with PD. It is a place to share feelings in a safe, caring environment as well as a place to gather information about resources.

Each session is 90 min. and is built around a specific topic (i.e. exercise, medication management, symptoms). The first two sessions are open to new members but the group is closed after the second session; a waiting list is created for the next time the group is offered. The group has room for a maximum of 15 participants and participants must commit to the full 8 weeks. The fall group will likely be held virtually through Zoom. For more information, please reach out to Joan Marsh-Reed at [Joan.Marsh-Reed@uvmhealth.org](mailto:Joan.Marsh-Reed@uvmhealth.org)



## HDSA Regional Support And Education Series 2022/2023

The Binter Center in partnership with Dartmouth-Health HD Clinic and the Huntington's Disease Society of America (HDSA) developed a successful virtual support and education series. This monthly series began in September 2022 and ran through June 2023. This series was attended by over 40 individuals living with HD and their families. Topics of this series included updates on research, understanding the role of a caregiver, the importance of exercise, legal consideration and future care planning, medication management and more! We're proud to have collaborated with Dartmouth-Health in bringing together presenters from the University of Vermont Medical Center, Dartmouth-Health, HDSA, and Boston Medical Center. This series is set to return in September 2023. For more information and presentation slides from this past series, please contact Brandolyn Bradley at [Brandolyn.bradley@uvmhealth.org](mailto:Brandolyn.bradley@uvmhealth.org).



## The CARERS Program for Dementia Family Caregivers

**Offered by: The University of Vermont Medical Center Dementia Family Caregiver Center and  
UVMHC Department of Neurology**

### *Summer/Fall Schedule 2023*

#### **What is the CARERS Program?**

CARERS (Coaching, Advocacy, Respite, Education, Relationship and Simulation) is an evidence based therapeutic group program that enhances the knowledge, skills, and competence of informal family caregivers of people with dementia. This program is based on the CARERS Program model developed by the Reitman Centre at the Sinai Health System of Toronto, Canada. Participants who complete the program report increased ability to cope and decreased burden.

#### **What is the TEACH Program?**

TEACH (Training, Education, and Assistance for Caregiving at Home) is a therapeutic, evidence based group designed for family members who are new to caregiving. This group meets for 90 minute sessions for 4 consecutive weeks and is led by a trained mental health professional. The program uses a model of supportive interaction, resource sharing, and problem solving.

#### **June-December 2023 CARERS and TEACH Groups:**

The Dementia Family Caregiver Center is currently offering 3 CARERS groups and 1 TEACH group through telemedicine, via a HIPPA compliant ZOOM video platform. These groups are intended for family members who have been actively providing intensive care to a family member with dementia. We offer separate CARERS groups for spouses and adult children.

#### **Logistical Information:**

**TEACH:** June 2-June 30, 2023. Time: 10:00am-11:30am (no group 6/16/23). Facilitator, Lisa K. Lax, LICSW, EdD

**CARERS Care Partners /Spouses:** September 15-November 11, 2023 (no group 10/27/23). Time: 1:30pm-4:00pm. Facilitators, Lori P. McKenna, LICSW and J Marsh-Reed, MA

**CARERS Adult Children:** September 6-October 25, 2023. Time: 4:00pm-6:00pm. Facilitators: Rhiannon Champagne, LICSW and co-facilitator to be determined.

**CARERS Care Partners/Spouses:** September 11-November 6, 2023 (no group 10/9/23). Time: 9:30am-12:00pm. Facilitators: Tara Graham, LICSW and Emily Mars-Raymond, MSW.

**For other groups anticipated but not yet scheduled please contact the Dementia Family Caregiver Center for updates at 802-847-2466.**

#### **Commitment:**

The CARERS program consists of 8 weekly sessions for 6 members. CARERS is designed to increase understanding of the behavioral and psychological symptoms of dementia and to address caregiver burden.

#### **Skills Learned:**

Cognitive behavioral therapy skills for problem solving practical needs and resource development. Communication skills (through simulation or role play) for managing emotions and improved communication with the person suffering from dementia or with others.

#### **Fees:**

Participation is generally covered by the caregiver's health insurance. Please contact us with any questions regarding potential barriers that may be addressed.

#### **Additional Information and How to Register:**

If you or someone you know is interested in finding out more about the CARER's program, or **if you would like to be considered for the group, please contact Lori P. McKenna, LICSW at 802-847-2466** or by email: [Lori.McKenna@uvmhealth.org](mailto:Lori.McKenna@uvmhealth.org). A pre-assessment interview is required prior to joining the group. We recommend that those with interest sign up soon; space may be limited.

## Movement Disorders Program Offerings

### Movement for PD

**Session runs June 6, 2023- August 24, 2023**

**Tuesdays & Thursdays.** No classes on July 4<sup>th</sup>, 25<sup>th</sup>, and 27<sup>th</sup>

**Tuesdays - 12:00 pm- 1:15 pm**, in-person at South Burlington Senior Center, 180 Market St. Masks recommended, all choices respected.

**Thursdays – 10:00 am- 11:15 am** via Zoom. Zoom link sent upon registration.

Classes taught by Sara McMahon, DfPD Certified Teaching Artist. For more information or to register, please visit <https://www.flynnvt.org/Events/2023/6/movement-for-parkinsons#register>

### PushBack at PD

For information on PushBack In-person classes please speak with your neurologist or your physical therapist about learning the PushBack circuits and registering for community classes. For information on community class times and locations, please contact Brandolyn Bradley at [Brandolyn.bradley@uvmhealth.org](mailto:Brandolyn.bradley@uvmhealth.org)

**PushBack Virtual classes:** Classes are held via Zoom.

**Mondays & Wednesday 2:00pm-3:00pm:** Seated version of PushBack (Sturdy chair required, minimal standing exercise, no floor exercise).

**Tuesdays & Fridays 2:00pm-3:00pm:** Standing version of PushBack (Wall space is ideal, sturdy chair and floor surface needed)

To register please contact Brandolyn Bradley at [Brandolyn.bradley@uvmhealth.org](mailto:Brandolyn.bradley@uvmhealth.org)

### PushBack at HD

**PushBack HD Virtual classes: Mondays & Thursdays 10:30am-11:30am.** Classes are held via Zoom. To register, please contact Parm Padgett at [Parmind-er.Padgett@uvmhealth.org](mailto:Parmind-er.Padgett@uvmhealth.org)

### Rock Steady Boxing

**Mondays 5:30pm-6:30pm, Tuesdays 4:45 pm- 5:45 pm, and Thursdays 4:15 pm- 5:15pm**

Classes are located at Collins Perley Sports and Fitness Center, St. Albans, VT  
To register, please email [stalbans@rsbaffiliate.com](mailto:stalbans@rsbaffiliate.com)

### Sing Loud for PD

Online singing class for people with PD and their care partners. There are just a few classes left in this session but a new session should be upcoming.

Please Contact: Sarah Cohen [sarah.cohen@stonybrookmedicine.edu](mailto:sarah.cohen@stonybrookmedicine.edu)

## Movement Disorders Support Groups

### Parkinson's Disease

Group	Meeting Schedule	Meeting Location	Contact Information
Brattleboro, VT	Monthly 2 <sup>nd</sup> Saturday 10 – 11:30 am	Brattleboro Memorial Hospital Tyler Room 17 Belmont Ave Brattleboro, VT <b>Virtual Group Currently</b>	Diane Nichols <a href="mailto:diane.nichols53@gmail.com">diane.nichols53@gmail.com</a> (603) 756-3089
Burlington, VT "People with Parkinson's (PWP) Support Group" (Only for people with PD.)	Monthly 3 <sup>rd</sup> Wednesday 12 pm – 1:30 pm	Fletcher Free Library 235 College St Burlington, VT <b>Virtual Group Currently</b>	Jennifer Pader LMSW <a href="mailto:westsidetherapy350@gmail.com">westsidetherapy350@gmail.com</a>
Middlebury, VT	Monthly 2 <sup>nd</sup> Saturday 1 pm – 2:30 pm	Contact Sara McMahon for information.	M Sara McMahon <a href="mailto:movementforparkinsons@gmail.com">movementforparkinsons@gmail.com</a>
Rutland, VT "The Fighters"	Monthly Last Monday 4 pm – 5 pm	Godnick Center 1 Deer St Rutland, VT	Andrea McQuade <a href="mailto:edau-qcma@comcast.net">edau-qcma@comcast.net</a> 802-775-5104  Lee Accavallo <a href="mailto:lee@royalvt.com">lee@royalvt.com</a> (802) 353-8838
St. Johnsbury, VT	Monthly 3 <sup>rd</sup> Friday 10:30 am-noon	Northeastern Vermont Regional Hospital Rm 126 (Main Floor) 1315 Hospital Dr St. Johnsbury, VT	Brendan Hadash <a href="mailto:bhadash@sover.net">bhadash@sover.net</a> (802) 748-8074
St. Johnsbury, VT <b>CAREGIVERS</b>	Monthly 1 <sup>st</sup> Wednesday 2 pm	Northeastern Vermont Regional Hospital Rm 126 (Main Floor) 1315 Hospital Dr St. Johnsbury, VT	Brendan Hadash <a href="mailto:bhadash@sover.net">bhadash@sover.net</a> (802) 748-8074

For other support group offerings, or if you are leading a support group not listed, please contact Binter Center Social Worker, Lori McKenna at: [Lori.McKenna@uvmhealth.org](mailto:Lori.McKenna@uvmhealth.org)



## About the PRECEDENT Study

In addition to movement symptoms, people with Parkinson's disease often have symptoms related to memory and thinking.<sup>1</sup> These symptoms may include difficulty planning, remembering, and staying on task, as well as trouble concentrating or finding the right words when talking. This is called **mild cognitive impairment**.

The PRECEDENT Study is evaluating the safety and efficacy of an investigational drug to see if it may improve cognitive function in participants with mild cognitive impairment due to Parkinson's disease.

Investigational drugs are not approved by a regulatory authority for any use, as the safety and efficacy have not been established.

### How Do I Qualify?

You may be eligible to participate if you:

- Are 50 to 75 years old
- Have been diagnosed with Parkinson's disease
- Have mild cognitive impairment related to Parkinson's disease (The study doctor can evaluate you if you haven't been diagnosed.)

*The study doctor will discuss additional eligibility requirements.*

You may invite a caregiver (also referred to as a study partner) to attend study visits and help you complete study activities.

Your safety while participating is the highest priority. If you have questions or concerns at any point throughout the study, a study staff member is available. The study staff can also tell you about their specific COVID-19 safety protocols.

Your participation in the PRECEDENT Study is completely voluntary. If you decide to participate in this research study, you are free to withdraw at any time, for any reason, without any penalty or effect on your medical care. Talk to your doctor if you have any questions about Parkinson's disease or its symptoms.

#### References:

1. Cognitive changes. Parkinson's Foundation. Accessed March 28, 2022. <https://www.parkinson.org/Understanding-Parkinsons/Symptoms/Non-Movement-Symptoms/Cognitive-Changes>

### If You Qualify and Decide to Participate:

- The study doctor will closely monitor you, your symptoms, and your overall health
- All study-related procedures and the investigational drug will be provided at no cost
- Transportation assistance may be available, if needed

If you have questions about research opportunities, please contact our

Research Coordinators:

Emily Houston, (802) 656-8974 [Emily.houston@med.uvm.edu](mailto:Emily.houston@med.uvm.edu)

Katherine Chan, (802) 847-1597 [Katherine.chan@uvmhealth.org](mailto:Katherine.chan@uvmhealth.org)

## A worldwide observational study for **Huntington's Disease** families

### **Do you have Huntington's disease? Are you related to someone who does?**

Ask your healthcare professional about participating in Enroll-HD, a worldwide observational study. We're collecting data from families in an effort to improve our understanding and treatment of HD.

There are no potential therapies or invasive procedures in this study.

Participants attend only one visit per year.

You'll be in position to learn about upcoming observational and clinical research studies.

**Be part of a worldwide effort to advance HD research.**

### **For More Information**

Contact your healthcare professional or visit [www.enroll-hd.org](http://www.enroll-hd.org)



If you or a loved one have been diagnosed with Parkinson's disease (PD), you or your loved one may be interested in participating in one of the TemPo Studies. They are a suite of three clinical research studies evaluating an oral investigational drug (tavapadon) to see if it may help improve PD symptoms that impact your movement and daily activities.

#### **You may be eligible to participate if you meet the following eligibility criteria:**

- Have been diagnosed with PD
- 40 to 80 years of age
- Have never received deep brain stimulation treatment

#### **All eligible study participants will receive at no cost:**

- Study-related consultation and care
- Study visits, tests, assessments, and procedures
- Study drugs (investigational drug or placebo)

**To learn more, speak with a member of the study staff.**

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### About KINECT-HD2

#### What is the KINECT-HD2 Study?

The use of valbenazine to treat chorea associated with HD is not approved by the U.S. Food and Drug Administration (FDA).

The purpose of this research study is:

- To evaluate the long-term safety and tolerability of valbenazine (valbenazine tosylate, NBI-98854) administered once daily
- To evaluate the long-term maintenance of effect of valbenazine to reduce chorea associated with Huntington disease (HD)

### Eligibility for KINECT-HD2

#### Who can participate?

KINECT-HD2 will enroll approximately 150 participants into the study who must meet several criteria, including:

- Male or female, ages 18 to 75 years
- Diagnosis of motor manifest HD
- Have sufficient chorea symptoms to meet study protocol criteria
- Willing and able to comply with the study instructions

## ORMIS-PD STUDY

We are looking for people to participate in this pilot research study of a novel investigational data and machine learning-based tool designed to augment clinical diagnosis of Parkinson's disease (PD) and to predict the course of an individual's PD based on the signs and symptoms captured using the ORMIS-PD tool.

This study only requires one visit and is only observational in nature with no change in treatment or testing needed. During the visit, we will ask you questions about your health, medications, and environment. Additionally, there will be a physical and neurological exam that includes questionnaires.

You may take part in the study if you meet the following criteria:

- You have been diagnosed with Parkinson's disease
- You are 40 years or older in age

For more information about the study, please contact the lead investigator, Dr. Deepak Gupta, or the study coordinator, Katherine Chan, at (802) 847-1597.



<https://www.topazstudy.org/>

**The TOPAZ study is done from your home!**

**TOPAZ is a clinical trial that will test if a medicine called zoledronic acid can prevent fractures and decrease the risk of dying in people with Parkinson's or parkinsonism.**

**You can join if you...**

- **Have Parkinson's or parkinsonism**
- **Are 60 years or older**
- **Have not had a hip fracture**

**Have you been diagnosed with Parkinson's Disease and also experience infrequent bowel movements or constipation?**

Dr. Lisa Deuel is leading a research study to determine if Pyridostigmine, an FDA approved drug for myasthenia gravis and used "off-label" to treat constipation, is a useful treatment for constipation in people with PD.

The study will take place at the UVM Medical Center Outpatient Neurology clinic and will last 13-15 weeks. There will be 3 in-person visits and phone calls throughout the titration and treatment periods.

You may be eligible if you:

- Have been diagnosed with PD
- Are able to take oral medications
- Have less than 3 bowel movements per week



For more information, please contact the study team at (802) 847-1597 or the Neurology clinic at (802)847-4589

Relaxing • Easy to Learn • Gentle • Sociable

# Seated Tai Chi

Fridays 10 - 11 a.m. in Williston

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Seated Tai Chi incorporates many principles of traditional Tai Chi: continuous and flowing movements; awareness of body alignment and position in space; sense of moving against resistance. The seated version allows those with movement disorders such as Parkinson's Disease, or with other physical limitations, to enjoy the benefits of this ancient practice. Participants leave feeling both deeply relaxed and also stimulated.

*Care partners are invited to participate.*



**Instructor: Adina Panitch**

Adina Panitch has been a Tai Chi practitioner for 13 years and is certified as an instructor by Tai Chi Vermont.

**Classes are held at The R.E.C. Zone**

**94 Harvest Lane, Williston**

Offered through Williston Recreation and Parks

Classes are free of charge. Voluntary donations will be accepted at each class to help defray costs.

**For more information, email [apanitch@aol.com](mailto:apanitch@aol.com) or call Williston Recreation & Parks at 802-876-1160**





# IN THIS CORNER, HOPE. FIGHTING BACK AGAINST PARKINSON'S



Rock Steady Boxing is an exercise program designed to improve the mobility, balance and strength of people fighting Parkinson's.

The program consists of:

- Non-Contact Boxing Drills
- Dynamic Warm Up and Stretching
- Balance and Mobility Training
- Cardio Training
- Strength Endurance Training
- ...and many other scientifically proven exercises to help patients with Parkinson's

Rock Steady Boxing is designed to quantify and continue research on the benefits of these specific exercises. RSB St.Albans welcomes people of all fitness and functional levels to join us – whether you are still able to jump rope or function best with a walker, come laugh, sweat and fight back with us!

**Call TODAY to find out more about this critical program.**

**ROCK STEADY  
BOXING  
ST. ALBANS**



## What We Offer

- 1. Classes:** RSB St. Albans offers group classes to accommodate varying degrees of Parkinson's/Fitness.
- 2. Camaraderie:** Fun and motivating coaches and friends for fighters and caregivers, aka "Cornermen!"
- 3. Support:** Our mission is to have our RSB Certified Trainers empower people with Parkinson's Disease to fight back! All exercises can be modified to the capabilities of the participant; we will make it work for you! You will be pushed, have fun and you will leave us wanting to come back for more!

890 Fairfax Road • St.Albans, VT 05478  
**802.527.1202 • StAlbans.RSBaffiliate.com**

BINTER CENTER NEWSLETTER

The Binter Center Newsletter is produced by The Frederick C. Binter Center for Parkinson's Disease & Movement Disorders.

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## Support the Binter Center

The Binter Center's budget is focused on providing top-notch clinical care, but the income from clinical care does not provide a margin for innovation and program development. This is why charitable gifts to support the Binter Center's educational, research and programmatic priorities are so important.

With your support, we at the Binter Center can continue to develop and expand *local* programs and services, participate in the latest clinical research, and provide education to fellow clinicians, students, and the community. Thank you for considering making a contribution!

Donate online at [UVMHealth.org/binter](http://UVMHealth.org/binter) or call (802) 656-2887.

