

Binter Center Newsletter

Spring 2021

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A Message from the Binter Center

2020 was no doubt a year of challenges and 2021 has been shaping up to bring us back together face-to face. The impacts of the Covid-19 global health crisis that has affected hundreds of thousands to millions of people around the world will be felt for years to come. As the country continues to emerge from the Covid-19 crisis, it's important to remember that we all play a role in promoting connectedness, belonging, resiliency, and following the "re-opening" process. Many within the Binter community have been dealing with the stress and anxiety related to social distancing, health concerns, and financial uncertainty. Today, it's more important than before that we reach out and be there for one another and share stories of hope and human connection. We are so close to being able to hug each other again, let's stay focused on the goal of being with our loved ones once again.

We at the Binter Center know the importance of exercise to mitigate the many symptoms associated with movement disorders as well as the vital role support groups play for both patients and their caregiver (s) to address the mental health components of both Parkinson's Disease, Huntington's Disease, and related disorders.

While we continue to work with the State of Vermont on re-opening guidelines, this issue of the Binter Center newsletter provides you with as many virtual resources as possible, so you may stay connected to the community you all have helped us to build. We want to encourage everyone to continue to take care of yourselves and if you have any questions or concerns, please do not hesitate to reach out to either the Binter Center, your primary care physician or our social worker. The Binter Center staff remain as always dedicated to our patients and their families and we wish for you all to be safe and healthy.

In Solidarity,

Dr. James T Boyd, Binter Center Director

Brandolyn Bradley, Binter Center Program Coordinator.

To help us all stay connected and informed, follow Dr. Boyd, Binter Center Director, on Facebook at <https://fb.me/bintercenter>

Staff Spotlight: Welcome Lisa Deuel, MD!



The Binter Center is excited to welcome Dr. Lisa Deuel to our team beginning in August, 2020. Dr. Deuel recently completed a 2-year fellowship in Movement Disorders at the University of Colorado, and is excited to join the team at the Binter Center. She is new to the state of Vermont, having grown up in a suburb of Rochester, NY and completed her education and training in NY state as well. Prior to moving to Colorado for fellowship, she completed medical school at Stony Brook University Medical Center on Long Island and Neurology residency at Albany Medical Center in Albany, NY, serving as chief resident during her final year of training. She first experienced the world of Movement Disorders at her job as a clinical research coordinator after college, and is

happy that she is able to continue caring for patients with Parkinson disease and other movement disorders. In addition to seeing patients in clinic, Dr. Deuel plans to work on some of the clinical trials that are offered at the Binter Center, and will also serve as the director of our new Movement Disorders fellowship program.

Dr. Deuel has her husband (a native New Englander) and two large, fluffy dogs in tow. Despite a general love for all things New England, she has no plans to ever become a Patriots fan.

A Message from former APDA VT Chapter President, Maureen Leahy

Greetings Vermont PD Community,

We are in the midst of beautiful Fall weather, with everything amazing that Vermont has to offer. Even during the COVID-19 pandemic, we find ourselves fortunate to live in a place where we can continually enjoy our serene surroundings.

I want to share with you some transitions underway for the American Parkinson Disease Association (APDA) in Vermont. As many of you may know, the APDA VT chapter has transitioned in the last few months and has joined forces with the APDA Massachusetts Chapter to combine efforts to enhance service to the PD community in Vermont. The Massachusetts Chapter already works collaboratively with volunteers and community providers to serve the northern New England region, and this partnership will allow the continuation of high-quality APDA services and resources to our area.

We have taken the time to introduce APDA MA Executive Director Bill Patjane to the Binter Center with the hope and expectation of a strong collaborative approach to continue providing you with the resources and support you need. The Binter Center has worked closely with the APDA VT Chapter for years, and we are grateful for all their support and partnership throughout the years.

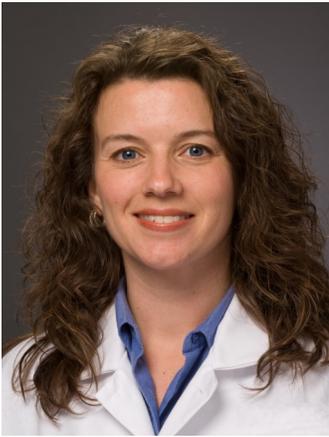
It has been a pleasure to work with all of you with the Vermont Chapter and to ensure this transition remains smooth, I will remain an APDA Board member of MA/VT, with a focus on advocacy and overseeing the delivery of services to the Vermont region.

Sincerely,

Maureen Leahy

Mood Changes in Movement Disorders

By Dr. Suzanne Kennedy, MD



“This shouldn’t be called a movement disorder, it’s really a BRAIN disorder” (patient description of their PD experience- 2019).

Our emotions are complex responses that are organized in our brain. The expression of emotion is dependent on the ability to detect a stimulus in the environment, interpret that stimulus, then send a signal to the appropriate area of the brain to display that emotion. It depends on the neurotransmitters (brain chemicals) and the neural connections throughout our brain. Similar to a road trip- the success of the trip depends on more than simply having a full tank of gas- it is impacted by the speed limits, detours, road conditions, weather and the function of the car.

The neurotransmitters influencing neuropsychiatric symptoms include:

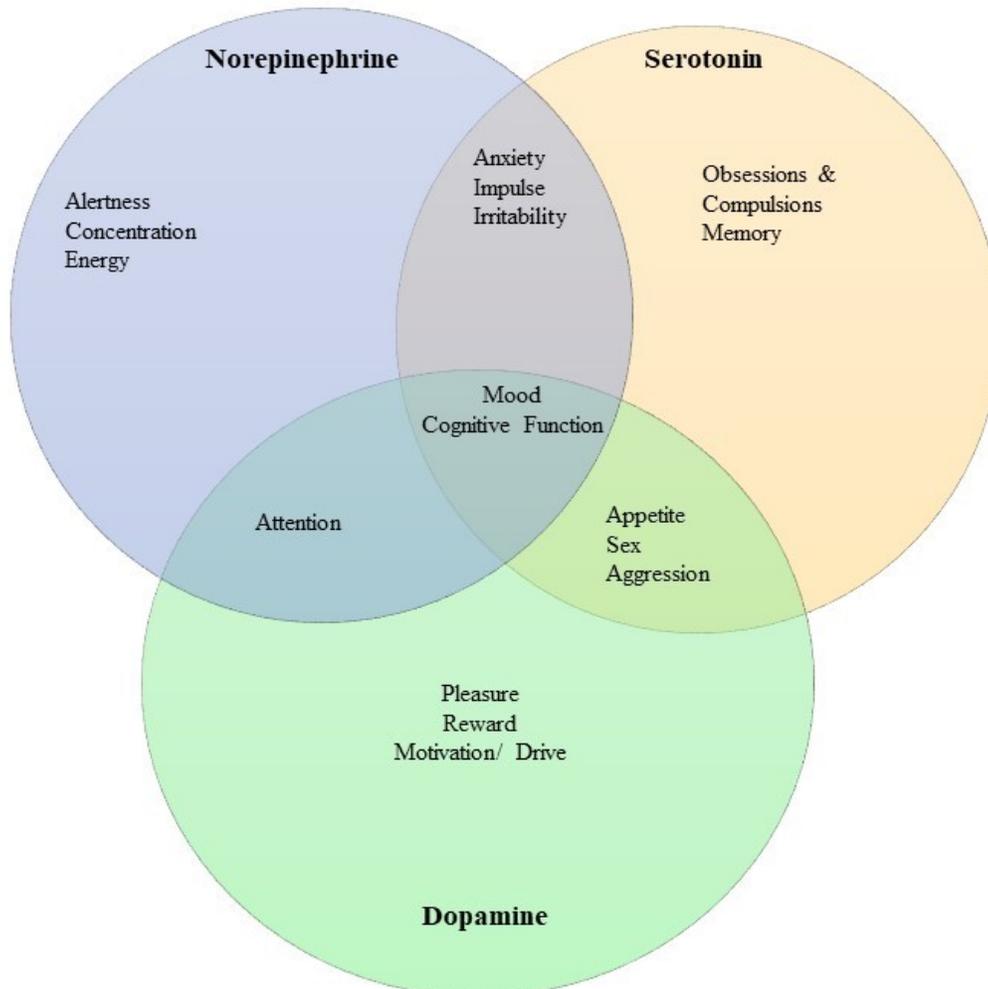
Dopamine (DA)- influences pleasure, reward/motivation and movements

Serotonin (5-HT)-influences mood, anxiety, perseverations

Norepinephrine (also called Noradrenaline) (NE)- influences concentration, energy

Acetylcholine (ACh)- influences memory, cognitive functioning

Any neurological disorder that affects these neurotransmitters (or their pathways) results in changes in emotional responses and cognition.



Mood Changes Cont.

Depression

A depressed or irritable mood can be a normal reaction to a particular situation. Persistence of these mood states however can interfere with daily functioning and be representative of a depressive episode. Depression is thought to occur when there is an alteration in the serotonin (also called 5-hydroxytryptophan or 5-HT) system. This can be triggered by a stressor or spontaneously develop due to changes in the brain. Besides contributing to low or irritable mood, depression can lead to alterations in sleep, interests, energy, concentration and appetite. Feelings of guilt, worthlessness, helplessness and suicide are common.

Treatment of depression varies. Research has shown that non-pharmacological approaches (without use of medicines) including Cognitive Behavioral Therapy (CBT) are beneficial. This type of therapy works well for individuals who have prominent negative thinking (cognitive distortion) which impacts their mood. In neurodegenerative disorders, medications are commonly used to target the changes that are occurring in the serotonin and norepinephrine systems which are contributing to the depressive symptoms.

The main classes of antidepressants used are:

- SSRIs (selective serotonin re-uptake inhibitors)- fluoxetine, sertraline, escitalopram, citalopram, paroxetine
- SNRIs (serotonin norepinephrine re-uptake inhibitors)-venlafaxine, duloxetine
- NDRI (norepinephrine dopamine re-uptake inhibitors)- bupropion
- TCA (tricyclic antidepressants)-nortriptyline, desipramine
- MAOIs (type B)-rasagiline, selegiline
- Other medications increasing serotonin- mirtazapine, trazodone, vortioxetine, vilazodone

As their names suggest, these medications primarily work by altering the receptors in the brain resulting in increased availability of the neurotransmitters. This change in brain receptors takes 4-6 weeks to be completed and explains why the response to these medications often takes a month to notice. Typically, mood is the last symptom to improve. Energy, sleep, concentration respond earlier. During this 4-6 week period, patients may be more at risk for suicide as symptoms do not all improve at the same rate. Choice of antidepressants is dependent on numerous factors including potential drug interactions, specific types of depressive symptoms, additional medical issues, family history and potential side effects.

Other treatments used for treatment of depression include:

- Full spectrum light therapy (during fall, winter months)- 30 min/day in fall and winter months
- ECT (electroconvulsive therapy)- 2-3 sessions per week for total of 6-12 treatments.
- rTMS (transcranial magnetic stimulation)- typically 5 sessions per week for 4-6 weeks

Anxiety

Anxiety is a normal physiological response to a stressor. This a protective measure to keep us safe from potential harm. An anxiety disorder occurs when this response system is not functioning properly. It could be a result of misinterpretation of environmental cues leading to cognitive distortions. Example: waking up to a loud noise at night and fearing someone has broken into your home. Anxiety can also be triggered by physical symptoms (dizziness, shortness of breath, rapid heart rate) which can then be misinterpreted as a heart attack leading to escalation of symptoms. Anxiety can also be triggered by neurochemical changes in the brain. It is thought to be impacted by abnormal regulation of serotonin and norepinephrine. Obsessive Compulsive Disorder (OCD) is an example of this. As with depression, treatments include CBT, mindfulness and meditation. Anxiety is fueled by a feeling of not being in control of something (environment, body, actions of others). Mindfulness and CBT help a person recognize this and regain a sense of control over the things that can be controlled and accept those things that are out of their control. Medications used for anxiety are the same ones used for depression.

Mood Changes Cont.

In addition, calming medications such as benzodiazepines ([lorazepam](#), [clonazepam](#), [alprazolam](#)) and antihistamines ([hydroxyzine](#)) have immediate effects, can be used in short term treatment. They do not target the source of the anxiety but rather work as an emergency relief. They are sometimes used for 1-2 months while implementing antidepressants or CBT. Long term use of **these** medications can lead to dependency (physical and psychological). They can slow cognition, breathing and increase risk of falls.

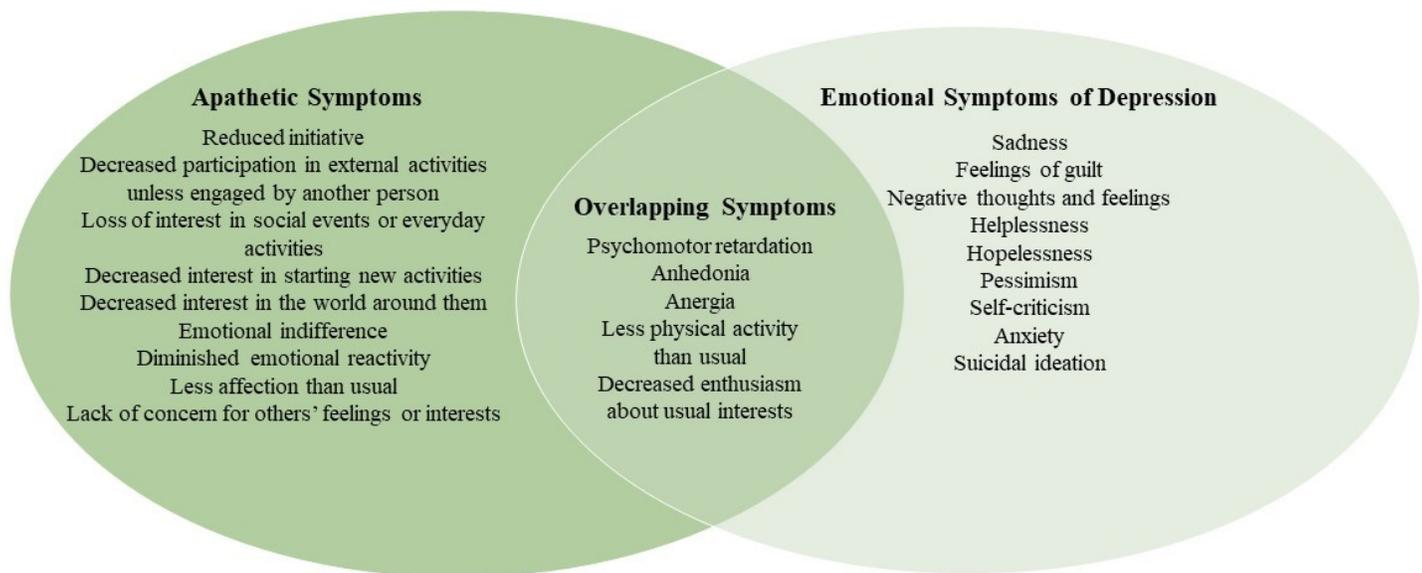
“What happened to your spark?”

Apathy

Apathy is a clinical syndrome under recognized in neurological conditions. It is derived from the Greek language and means: “a”- lacking “pathos”- passion Apathy is a result of changes in the brain that impact one’s drive/motivation and follow through. It can alter someone’s emotions (affective apathy), behaviors and cognitive functioning. Although there are no formal medical criteria for apathy, it is thought to be a syndrome of symptoms including:

- absence/suppression of emotion
- lack of motivation
- lack of sense/purpose
- sluggishness
- detachment

Loved ones often feel as though the individual has become “lazy” or “uncaring”. This can lead to more distress within the family unit as it affects self worth of the patient, interactions with loved ones and overall quality of life. It can interfere with a person’s commitment to treatment **and preventative** strategies as well.



Mood Changes Cont.

Apathy can be misdiagnosed as depression due to the presentation of withdrawal and reduced engagement. Unlike those experiencing depression, patients with apathy often do not have persistent low/irritable mood, prominent guilt, hopelessness or suicidal thoughts. They may appear indifferent to the changes that are happening, have reduced productivity and report muting of emotions but they continue to experience enjoyment and interest in things that excite them. This syndrome is thought to result from a reduced ability to *respond* to rewards (altered reward pathway) not a reduced willingness to engage in effort.

In order for a task to be carried **out**, **several** steps must occur. There must be:

- motivation
- planning the steps for completing the task
- initiation of the task
- stamina/enjoyment to continue the task

Many alterations in the brain can interfere with any of these steps and lead to apathy presentation. Dopamine is known as the “pleasure” neurotransmitter. It causes certain people to become addicted to activities that have dangerous consequences (ie: gambling, speeding). It is the reason for the “runner’s high” that athletes describe. In many movement disorders, malfunctioning of the dopamine system is suspected to cause apathy. Other neurotransmitters that may contribute to apathy include norepinephrine and acetylcholine. The malfunctioning leading to apathy may be complex involving both the pathways and the availability of all of the neurotransmitters.

Apathy is commonly seen in Parkinson’s Disease, Huntington’s Disease, Multiple Sclerosis, dementias, stroke, schizophrenia and TBI (traumatic brain injury). The prevalence is difficult to estimate because no strict criteria exist for apathy. Rating scales have been developed to better identify apathy in patients. To date, research has been limited on medications for apathy. Antidepressants have not been helpful in reducing apathy but may be beneficial in those who have coexisting depression or anxiety. Sometimes antidepressants may increase apathy symptoms. Stimulants (amantadine, methylphenidate, dextroamphetamine, atomoxetine, modafinil) have shown some possible benefit for apathy due to their impact on increasing dopamine and norepinephrine. Cholinesterase inhibitors (such as galantamine, donepezil, rivastigmine) have shown mixed results in apathy. They increase acetylcholine and are thought to interact with the dopamine pathways. Dopamine has been explored in many research trials. Unfortunately levodopa replacement does not appear to reduce apathy. Dopamine agonists (such as rotigotine) have shown mixed results in patients with TBI, dementia and PD.

Despite the limitations from apathy, individuals are often surprised by their ability to complete and enjoy a desired activity when they are joining in that task completion with others. Humans are social beings, we naturally want to engage with others and share the work. The most successful approach to apathy is a behavioral approach that relies on our natural desire to engage/share with other and the power of habits.

Due to the impact of cognitive slowing on task completion, strategies include:

- simplifying tasks to avoid multiple steps
- having break times to reduce fatigue
- sharing the activity with another person (equal responsibility)
- structured days with consistent sleep/wake cycle
- exercise (2.5 hrs per week)
- habituating the times of the desired activity
- using external cues (signals) to remind, encourage the task
- encouraging brief trial of a task even if initial response is “no” (to account for common delayed reward response, delayed motivation)
- AVOID “to do” lists if the responsibility is placed entirely on the individual
- Encourage group events (increases accountability, support, team work)

The assessment of neuropsychiatric symptoms in movement disorders requires a multidisciplinary approach for diagnosis and management. The team at the Binter Center for PD and Movement Disorders works together to address all aspects of brain functioning. Through education and a personalized approach, we focus on maximizing functioning and quality of life for the patient and those sharing the life journey with them.

Virtual Support and Movement Offerings

Exercise

PushBack at Parkinson's- PushBack is a medically advised, community supported group exercise program designed by physical therapists to address the main movement problems associated with PD. **Please contact** Margret Holt at margaret.holt@uvmhealth.org for more information.

PushBack at Huntington's- PushBack is a medically advised, community supported group exercise program designed by physical therapists to address the main movement problems associated with HD. **Please contact** Parm Padgett at parminder.padgett@uvmhealth.org for more information.

Movement for PD- Weekly movement class offered virtually. The program's fundamental working principle is that professionally-trained dancers are movement experts whose knowledge about balance, sequencing, rhythm and aesthetic awareness is useful to persons with PD. **Please contact** Sara McMahon at: movementforparkinsons@gmail.com

Speak Out/Loud Crowd - Amazing voice program offered through University of VT Health Center for those who live in VT. **Please Contact:** Ashley.Michaelis@uvmhealth.org

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

Virtual Support Groups

Meets the 2nd Saturday of the month from 1pm– 2:25 pm via Zoom. Please contact Sara McMahon at: movementforparkinsons@gmail.com.

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

APDA Sponsored:

Caregivers Support Group, Thursdays at 11 am Est:

<https://apdaparkinson.zoom.us/meeting/register/tZMkfuCgrjsqEtQ4uEBGQfv3JlpF0FoMHrXa>

Meeting ID: 879 9980 0080

Parkinson's Support Group Thursdays at 12 pm Est:

<https://apdaparkinson.zoom.us/meeting/register/tZEtcO2hrDMiGtdm5rhF2cIFX6xlE6Qcjfoe>

Meeting ID: 850 7492 8803

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



"Ask the Doctor" Webinar Series on Parkinson's Disease

The first Tuesday of the month starting May 4, 2021
6:00pm EST

[REGISTER HERE](#)

[DONATE NOW](#)

Do you have questions or concerns about Parkinson's Disease?

The Binter Center for Parkinson's Disease & Movement Disorders is back with the "Ask the Dr." web series! Binter Center Physician, Dr. Lisa Deuel will answer questions live about symptoms, treatments, and living with PD. This series will be held the first Tuesday of the month starting May 4, 2021, through December 7, 2021, at 6 pm EST.

Questions will be answered in the order in which they are received. You will also have the option to keep your questions anonymous. This webinar series is free but donations are welcome.

Questions? Please Contact
Brandolyn Cudhea,
Binter Center Program Coordinator
Brandolyn.Cudhea@uvmhealth.org

Clinical Research at the Binter Center



A Clinical Study for Huntington Disease Chorea

Now Enrolling!

What is the KINECT-HD Study?

Valbenazine is being studied for the treatment of chorea associated with HD. The use of Valbenazine to treat chorea associated with HD is not approved by the U.S. FDA.

The purpose of this research study is:

- To evaluate the effectiveness of valbenazine to reduce chorea associated with HD
- To evaluate the safety and tolerability of valbenazine.

Who can participate?

KINECT-HD will enroll approximately 120 participants into the study who meet criteria such as:

- Ages 18-75 years
- Diagnosis of motor manifest HD
- Willing and able to comply with the study instructions

How long is the study?

Participation in this study consists of 9 total study visits over the course of 18 weeks.

For more information, contact the study team below or visit: <http://www.KINECT-HD.org/>

Clinical Research at the Binter Center

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

Welcome to the BouNDless Research Study

A multicenter, randomized, active-controlled, double-blind, double-dummy, parallel group clinical trial, investigating the efficacy, safety, and tolerability of continuous subcutaneous ND0612 infusion in comparison to oral IR-LD/CD in subjects with Parkinson's disease experiencing motor fluctuations (BouNDless)

About the Study

As Parkinson's disease progresses, symptoms become more complex and more debilitating. There is an unmet medical need, and clinical research is important to get new safe and effective drugs to individuals living with Parkinson's disease.

The purpose of this clinical research study is to **investigate the efficacy, safety, and tolerability of continuous subcutaneous** infusion of an investigational treatment in comparison to oral levodopa/carbidopa in patients with Parkinson's disease.

To qualify for this study, individuals must:

- Be at least 30 years of age
- Have been diagnosed with Parkinson's Disease
- Currently be taking at least 4 doses per day of levodopa/dopa decarboxylase inhibitor (LD/DDI), or at least 3 doses per day of extended-release LD/DDI (e.g., Rytary®)
- Currently experience motor fluctuations for 2 hours or more every day in the "OFF" state during their time awake

Participants in this research study will be closely monitored by a study doctor and will receive all study-related care at no cost to the participant. Compensation for travel may be available.

During the treatment period, a helpline will be available for subjects and study partners to call any time they encounter any difficulties. Study-related home support will also be available.

Clinical Research at the Binter Center Cont.



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.

V1-20100628-US-ENG-PI-10P

TOPAZ
TRIAL OF PARKINSON'S AND ZOLEDRONIC ACID

topaz.eurekaplatform.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

If you have questions about research opportunities, please contact our Study Coordinators at:

Emily Houston, (802) 656-8974 Emily.houston@med.uvm.edu

Katherine Chan, (802) 847-1597 Katherine.chan@uvmhealth.org

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 or call (802) 656-2887.

