A Message from the Binter Center

In this issue of the Binter Center newsletter, we focus our attention on understanding the structure and importance of conducting research and providing information on current clinical trials. The significance of clinical trials provides a scientific basis for advising and treating our patients. Participating in clinical trials can not only help to provide a valuable contribution to the progress of research but is also a way for you to play a more active role in your own healthcare. In this issue, you'll learn about two research studies being conducted by two of our physicians and also ways for you to get involved in current clinical trials. At the Binter Center, we strive to provide our movement disorders community with the most up-to-date information to ensure our patients, advocates, partners, and programs can continue to ensure our community remains strong.

In Solidarity,
Dr. James T. Boyd, Binter Center Director
Brandolyn Bradley, Binter Center Program Coordinator
Staff Spotlight: Binter Center Research Coordinator, Emily Houston!

The Binter Center is excited to introduce to you Emily Houston, Binter Center’s Clinical Research Coordinator. Emily grew up in Jericho, Vermont, and went on to graduate from the University of Vermont with a Bachelor of Science in Neuroscience. Emily has been with the Binter Center for 11 years, having a passion for neurological research. She is currently a Ph.D. candidate at the UVM Larner College of Medicine in the Clinical and Translational Science program. Emily has always had an interest in studying Neurodegenerative disease, however, movement disorders have become a true passion due to her interests in how exercise, diet, and other lifestyle factors can impact the mind and body.

Emily is married with two children and enjoys many forms of exercise, from running and biking, to strength training and martial arts. Recently, she became a coach for Rock Steady Boxing, an exercise program for people with PD that runs classes in St. Albans. Emily looks forward to continuing her career in research, gaining a better understanding of the impact living habits have on quality of life among those living with movement disorders.

Clinical Studies at the Binter Center

Here at the Binter Center, there is a strong emphasis on research. It’s important to us to not only read about and study scientific advances or changes that may impact our patients, but to actively participate in studies that could bring new and improved treatments to our communities. Clinician-scientists at the Binter Center also collaborate with other Investigators and study groups around the world to learn more about the underlying causes of certain diseases that are treated in our clinic. Below, we’ll describe the different types of research the Binter Center conducts, and ways you can learn more about participating.

What is an Observational Study?
Observational studies do not involve the testing of new therapies, but give researchers the opportunity to observe and collect information about the volunteers which may be helpful in better understanding certain characteristics, changes, or associations. These types of studies are not designed to determine causality, but they can assist Investigators in coming up with questions or hypotheses to test in clinical trials.

Types of observational studies include:

**Case Study or Case Series:** Unusual cases found in one or more patients are described in great detail. The cases are observed in their natural setting, and Investigators can come up with hypotheses based on their findings.

An individual was exposed to a toxic substance and developed abnormal movements - A researcher could do a case study on the symptoms, medical history of the patient, type of chemical they came into contact with, if certain treatments resolved the condition, etc.

**Ecological Study:** These studies are often used to measure the prevalence and incidence of a condition or disease, by observing larger groups of people that share a characteristic such as location.
Researchers can compare the rates of Parkinson’s disease in different geographic regions and contribute this data to further analyses of risk factors in those areas.

Cross-Sectional Study: Data from a population or representative sample is analyzed at one specific moment in time, typically with the goal of evaluating the relationship between an exposure and an outcome.

*Dr. Data looks at information collected from Medicare beneficiaries in New England from 2021 and examines how many people have Essential Tremor, and if there is a significant difference between those that identify as male or female.*

Case-Control Study: Two groups of people are compared – one group with the condition of interest and the other without. As an observational study, no intervention is applied to change the condition, but they are observed for possible causes or risk factors.

*An Investigator collects information from people with a movement disorder and from a group of age-matched controls, including medical and lifestyle histories. They are primarily interested in exposure to tobacco products and neurological conditions.*

Cohort Study: These studies follow groups of people over time, sometimes years, to observe if some develop specific conditions, or how symptoms may change. Rather than case-control studies, cohort studies are prospective, or moving forward in time as opposed to looking backwards.

*At UVM, we participate in Enroll-HD, an observational study for Huntington disease (HD). Participants are people with HD, at-risk of having HD, family members and community controls. They have annual visits, where we collect information on motor symptoms, mood, and thinking.*

**What is a Clinical Trial?**

Clinical trials involve the use of an intervention or treatment that could be medical, surgical, or behavioral. By assigning study participants to groups, which can vary based on things like dose, or if the treatment is active (the actual therapy) versus placebo (inactive), we can learn more about how safe and/or effective these are for people with specific movement disorders. In the Binter Center, the majority of our clinical trials involve a study drug which is designed to work on a symptom or set of symptoms; though we recently began conducting studies with potential disease-modifying agents, or drugs that could slow the progression of Parkinson’s disease.
Clinical Studies Cont.

The full process of identifying a promising treatment, research, development, and FDA approval can take up to 12 years. While this sounds daunting, our team is typically joining studies well into the testing process, at Phases 2 and 3.

**PHASES of a CLINICAL TRIAL**

**Phase 1**

*SAFETY*
- Duration: Several months
- Evaluate safety
- Gather information about how a drug interacts with the human body

*DOsing*
- Duration: Several months
- Further evaluate safety
- Monitor side effects
- Check which dose works best
- Check effectiveness

**Phase 2**

*SAFETY AND EFFICACY*
- Duration: Several years
- Confirm effectiveness
- Monitor safety

**Phase 3**

*POST MARKETING SAFETY AND EFFICACY*
- Gather information on the drug’s effect in various populations and any side effects associated with long-term use

**Phase 4**

Source: [www.slhn.org](http://www.slhn.org)

**Phase 1** trials are sometimes referred to as the “first in humans” studies, as the treatment makes it way from the laboratory, where it was tested in animals to determine the safety and mechanisms of action. Phase 1 trials are typically very small, with about 20 to 80 healthy volunteers, and the focus is safety- what dose can be well-tolerated?

**Phase 2** studies are usually when the treatment is applied to individuals with the disease we’re studying. The sample size is increased to around 200-300 people, and we continue to study the safety as well as the effectiveness of the drug or therapy.

**Phase 3** trials will take the information from Phase 2, for instance, which dose was safe and effective, and test this in several hundred people with the disease. For both Phase 2 and 3, our institution joins many institutions across the country or world, all looking for eligible participants. If the trial results are positive, the company that produced the drug will apply for FDA approval.

**Phase IV**, or Post-marketing trials, continue to collect data on the safety and effectiveness of the therapy, as it is being used in larger and more diverse groups, as well as for a longer period of time than the initial clinical trials.
Clinical Studies Cont.

Occasionally, our Investigators have a question or hypothesis that they want to test or learn more about, and end up developing and conducting their own studies. These Investigator-initiated studies, as they’re called, can range from observational studies to smaller-scale trials of a therapy (a pilot study). We work with funding agencies, or apply for internal grants, that allow us to dedicate time and resources to important and interesting topics. It also allows us to involve our local patients in studies that could contribute to larger studies or impact what we know about certain diseases.

All research studies must be submitted to an Institutional Review Board (IRB), which ensures that the safety and well-being of study participants are protected, and that the researchers are qualified through education and training. It is of the upmost importance that we follow principals that lead to high-quality, ethical research. A few examples are: ensuring that there is social value that justifies the risks, having a strong scientific basis and clear methods, and respecting the well-being and privacy of participants.

Participating in a clinical trial is a personal choice, but we have found that many of our participants have a positive experience and feel like they were able to have an active role in their care, while potentially helping others in the future. If you are interested in learning more about research trials at the Binter Center, please let your Neurologist know, or reach out to one of our Clinical Research Coordinators, who can let you know about the studies we are currently running and if you meet the eligibility criteria for a study.

Emily Houston, Emily.houston@med.uvm.edu, (802)656-8974
Katherine Chan, Katherine.chan@med.uvm.edu, (802)847-1597

Parkinson Disease and Constipation

By: Lisa Deuel, MD

Did you know that up to 80% of individuals with PD experience constipation at some point during their disease course? Constipation is a common problem associated with PD, and to some people it can be more bothersome than movement symptoms like tremor and stiffness. Constipation is one of the “prodromal” symptoms of PD, meaning it can start years or even decades before the common movement symptoms that we think about and well before someone is diagnosed with PD. Of course, just having constipation doesn’t mean that you will get PD in the future, but we find that a lot of people who are diagnosed with PD report constipation going back many years. It is important to recognize and treat constipation because when it is not treated it can lead to poor quality of life.

What is constipation? When we think about constipation, most people think it means that you don’t go to the bathroom often enough. According to the ROME IV Criteria for Functional Constipation, there are other symptoms that can indicate you have constipation, and you must have at least 2 of these symptoms to be diagnosed:

- a. Have fewer than 3 bowel movements per week
- b. Strain at least 25% of the time when you are trying to go to the bathroom
- c. Have lumpy or hard stools at least 25% of the time
- d. Feel like you can’t fully have a bowel movement at least 25% of the time
- e. Feel like stool is blocked trying to exit the bowels at least 25% of the time
- f. Require manual removal of stool from the bowels at least 25% of the time
Constipation Cont.

Why do people with PD have a higher risk of constipation compared to those who don’t have PD? The most common theory is that the abnormal folding of alpha-synuclein, the protein that builds up in the brain of people with PD, actually starts in the gut. Scientists have found the same abnormal alpha-synuclein in the nerves that send signals to move food through the gut, so if these are not working properly the process can slow down and cause constipation. We are not sure what triggers the proteins to start folding incorrectly, but once the process starts, it seems like it passes backward from the gut up to the brain.

How do we treat constipation? There are many treatment approaches for constipation. First, we often start by recommending that people increase their water/fluid intake up to 64 ounces per day. That’s about 2 liters, so think about a large soda bottle. We also recommend dietary adjustments – increasing the amount of fiber is a great way to bulk up stool, and bulky stool is easier to pass. We don’t really have specific treatments for people with PD who have constipation, and we use the same treatments that anyone else without PD would use if they have constipation. This includes a number of oral pills and solutions, as well as suppositories and enemas if symptoms are severe. People can take medications on a daily basis or take them as-needed when symptoms are bothersome.

Typical medication options to treat constipation

<table>
<thead>
<tr>
<th>Dietary adjustments</th>
<th>Increase hydration</th>
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<tbody>
<tr>
<td></td>
<td>Increase fiber intake</td>
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<tr>
<td>Bulking agents</td>
<td>Methylcellulose powder</td>
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<td></td>
<td>Polycarbophil (e.g., Fibercon)</td>
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<td></td>
<td>Psyllium (e.g., Metamucil)</td>
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<tr>
<td>Stool softeners</td>
<td>Docusate sodium (e.g., Colace)</td>
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<tr>
<td>Osmotic laxatives</td>
<td>Polyethylene glycol (e.g., MiraLax)</td>
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<td></td>
<td>Magnesium hydroxide (e.g., Milk of Magnesia)</td>
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<td></td>
<td>Magnesium citrate (e.g., Citroma, Citro-Mag)</td>
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<td></td>
<td>Sorbitol</td>
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<td></td>
<td>Lactulose (e.g., Acilac, Enulose)</td>
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<tr>
<td>Stimulant laxatives</td>
<td>Senna (e.g., Senokot, Ex-Lax)</td>
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<tr>
<td></td>
<td>Bisacodyl (e.g., Dulcolax, Correctol)</td>
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<tr>
<td>Other</td>
<td>Lubiprostone (e.g., Amitiza)</td>
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<tr>
<td></td>
<td>Linaclotide (e.g., Linzess)</td>
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<tr>
<td></td>
<td>Probiotics</td>
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</table>

What research is going on? At the University of Vermont Medical Center, we are interested in whether a drug called pyridostigmine (e.g., Mestinon) would be helpful for treating constipation in people with PD. Pyridostigmine is a drug that stops the body from breaking down a neurochemical called acetylcholine. With more acetylcholine available, the nerves are able to send signals to the gut more easily, helping to move food through the GI tract. We use this medication in other neurological conditions like myasthenia gravis and orthostatic hypotension, so we think that it is relatively safe in people with neurological disorders.
Constipation Cont.

We are starting a small open-label trial to test pyridostigmine for patients with PD who have constipation. Open-label means that everyone who enrolls in the study will receive the active drug (no placebo group). People who are interested will meet with the study team to make sure they meet all of the eligibility criteria and will complete a journal for a month recording information about their bowel movements. They will then come back to clinic for a baseline study visit where they will complete some tests with the study team, receive the study medication, and continue to record their bowel movements in a journal. Participants will work closely with the study team to slowly increase the study medication to a maximum dose, and then will continue to take that dose for 4 weeks. At the end of the study, participants will return to clinic for more assessments to end their participation.

The whole study should take between 13-15 weeks, with 3 visits to the clinic and a few phone calls in between.

If you are someone with PD who has fewer than 3 bowel movements per week and are interested in participating in this clinical trial, please reach out to our study coordinator Katherine Chan at (802) 847-1597 to see if you may be eligible to participate.

Ontology-based, Real-time, Machine Learning Informatics System for Parkinson’s Disease (ORMIS-PD)

By: Deepak Gupta, MD

Currently, there are no definite laboratory or imaging tests available to diagnose Parkinson’s disease (PD), and it is clinically diagnosed by primary care physicians, general neurologists, and movement disorders neurologists based on presence of key movement symptoms and signs, such as slowness of movement (bradykinesia) with rest tremor and/or increase in muscle tone (rigidity), with or without non-motor symptoms. However, initial clinical diagnosis has been shown to be frequently inaccurate when compared to the gold standard neuropathological diagnosis in research studies, as the presenting clinical features can also be present in other conditions related to PD, such as atypical Parkinsonian disorders / syndromes (namely, Lewy body disease, multiple system Atrophy, progressive supranuclear palsy, corticobasal degeneration) or secondary parkinsonism (for example, drug-induced parkinsonism, vascular parkinsonism, etc.). The International Parkinson and Movement Disorders Society (MDS), a leading organization of PD specialists, has created criteria for diagnosing patients into two levels of diagnostic certainty, that is, “clinically established” and “clinically probable” PD, and these criteria have been shown to have high sensitivity and specificity. However, these criteria follow a complex algorithm and thus nearly impossible to implement for primary care clinicians and general neurologists, and relatively impractical in their current format even for movement disorders specialists.

Beyond the diagnosis, the most frequent question asked in the clinic by the PD patients and their caregivers is that of prognosis, that is, how will the patient’s disease progress in the future? To this end, the heterogeneity of PD prognosis is quite remarkable, sometimes referred as “many faces of Parkinson’s disease”, which has been formally recognized to represent distinct subtypes of PD, specifically, “mild-motor-predominant”, “intermediate”, and “diffuse malignant”. Such proposed subtypes have been linked with varying rates of progression, and directly linked with underlying complexity of molecular changes occurring in the nervous system in PD.
For example, although alpha-synuclein (α-Synuclein) protein misfolding and accumulation in the form of Lewy bodies is considered a pathological hallmark of PD, a variety of genes and/or proteins are also implicated in PD, such as Leucine-rich repeat kinase 2 (LRRK2) and glucocerebrosidase (GBA), in addition to various genetic changes in the α-Synuclein gene.

With respect to PD in veterans, several studies have shown that exposure to neurotoxins, such as Agent Orange, are associated with increased risk of PD. Importantly, PD is a presumptive condition for veterans who served in a certain place (Vietnam, Korean Demilitarized Zone, and Camp Lejeune) during a certain time period, under the assumptions that they might have been exposed to toxins (such as Agent Orange). However, there have been limited or no research on whether there are differences in PD associated with Agent Orange exposure in veterans versus PD not associated with Agent Orange exposure in non-veterans, especially with respect to the accuracy of diagnosis.

Above summarized issues are two of the most pressing challenges faced by clinicians, researchers, patients and their caregivers in the field of PD. Furthermore, there are no tools available to the clinicians or researchers at the point-of-care in clinic or in research studies, respectively, for classifying an individual patient on the MDS PD clinical criteria or forecast prognosis on relevant outcome measures. As part of the ORMIS-PD research project, we are taking a novel approach to developing potential solutions for addressing these unmet needs. In aim 1, ORMIS-PD is being designed to enable capturing of the patient’s clinical information in a curated and intuitive fashion using the Parkinson & Movement Disorders Ontology (PMDO) and a touch-screen interface, respectively. Then, ORMIS-PD will automatically reconcile the collected information with the Movement Disorders Society criteria for computer-aided diagnosis of the patient. Subsequently, the ORMIS-PD platform will automatically calculate the prognosis score from the collected information, and the apply artificial intelligence method, driven by data of a large PD database Parkinson Progression Marker Initiative, for forecasting future changes in prognosis score. In aim 2, clinical information of PD patients will be collected using ORMIS-PD for two groups, one group with Agent Orange exposure and another group without Agent Orange exposure, at two sites, namely, University of Vermont Medical Center and Oregon Health & Science University/Portland Veterans Affairs Medical Center. Afterwards, the two groups will be compared with respect to their ORMIS-PD generated diagnosis and prognosis score.

The ORMIS-PD project is a research collaboration among University of Vermont (UVM), Case Western Reserve University (CWRU), and Portland Oregon Health & Sciences University (OHSU) / Portland VA Medical Center (PVAMC), and has been funded from a competitive $400,000, two-year grant starting September 2021 from the Department of Defense (DOD). Principal investigator Deepak K. Gupta, MD, Movement Disorders Neurologist at the Binter Center, and Assistant Professor of Neurological Sciences at UVM is leading this collaborative, and multi-site project. In addition to Dr. Gupta, team investigators include James Boyd, MD, Director of the Binter Center, and Professor of Neurological Sciences at UVM; Satya S. Sahoo, PhD, Associate Professor of Computer Science and Director of Biomedical Health Informatics PhD program at CWRU; and Amie Hiller, MD, Associate Professor of Neurology at OHSU/PVAMC. Other members of team include Katherine Chan, Research Coordinator in department of neurology at UVMMC, Ms. Katrina Prantzalos, Postdoctoral Graduate Student at CWRU, Ms. Brenna Lobb, Research Coordinator at OHSU/PVAMC.

We are hopeful that successful completion of this research project will lay the groundwork for application of artificial intelligence approaches for improving PD diagnosis and predicting progression, and provide new information on potential differences in diagnostic classification and prognosis measures between neurotoxin-associated PD and idiopathic PD.
PRESS Program
Parkinson Roadmap for Education and Support Services

There are several future directions of ORMIS-PD, such as, expansion to include context of atypical parkinsonian disorders, integration with patient-centered digital measures obtained using mobile health technologies, and predictive analytics for treatment responses and clinical trials for PD and related disorders.

Pictured above (from left to right and top to bottom): Ms. Lobb, Dr. Gupta, Dr. Sahoo, Dr. Hiller, Ms. Prantzalos, Ms. Chan, and Dr. Boyd from the ORMIS-PD project virtual kick-off meeting on September 3rd, 2021.

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
Movement Disorders Program Offerings

Movement for Parkinson’s Disease
June 9, 2022 - August 27, 2022, Thursday and Saturday morning 10:00am - 11:15am (This class is now a hybrid offering with Thursday being virtual and Saturday in-person at the Flynn and online)
All classes taught by Sara McMahon, Dance for PD® Certified Teaching Artist. For information or to register, please visit https://www.flynnvt.org/Events/2022/8/Movement-for-Parkinsons

PushBack at Parkinson’s Disease

PushBack In-person classes
Combat Fitness: Mondays & Wednesdays 12:30 pm- 1:30 pm (please contact Combat Fitness to register at 802-655-5425)
HammerFit Gym: Tuesdays & Thursdays 12 pm-1 pm (Please contact Abby at HammerFit to register abby@hammerfit.com)
The Barre RehabGYM: Tuesdays and Fridays 4 pm- 5 pm (please contact the gym directly at 802-479-4001 to register)

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)

For more information please contact Binter Center Program Coordinator, Brandolyn Bradley at Brandolyn.bradley@uvmhealth.org

PushBack at Huntington’s Disease (Virtual)

Tuesdays & Fridays 10:45am-11:45am. Classes are held via Zoom. To register, please contact Parm Padgett at Parminder.Padgett@uvmhealth.org

Rock Steady Boxing

Mondays 5:30pm-6:30pm, Thursdays 3:00pm-4:00pm, and Saturdays 11:30am-12:30pm
Classes are located at Collins Perley Sports and Fitness Center, St. Albans, VT
To register, please email stalbans@rsbaffiliate.com

Tai Chi

Fridays 10:00 am Classes are held via Zoom. To register please contact Adina Panitch at 802-288-1555 or apanitch@aol.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
## Movement Disorders Support Groups

### Parkinson’s Disease

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

TOPAZ
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

INFORMATION ABOUT THE PADOVA CLINICAL STUDY FOR PARKINSON’S DISEASE

We are conducting PADOVA to find out whether a new investigational drug could slow disease progression for people with early Parkinson’s disease.

THE STUDY IN BRIEF

The study will last for at least two years and includes a screening process, treatment period and follow-up period. During the treatment period, you’ll receive either the investigational drug or a placebo (a lookalike drug containing no active medicine) in addition to your regular Parkinson’s treatment. Both study drugs (the investigational drug and placebo) will be given as intravenous (IV) infusions (sometimes called a ‘drip’). If you choose to take part, you’ll need to visit a study clinic approximately once every four weeks (at least 22 times in total). This is so that we can closely monitor your general health and see how you are responding to your assigned study drug.

Who can take part in this study?

We’re looking for approximately 575 people to join, who, among other things:

- Are aged between 50 and 85
- Have been diagnosed with Parkinson’s disease for between 6 months and 3 years
- Have been receiving either MAO-B inhibitors or levodopa monotherapy for at least 6 months
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

The TEMPO Studies

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.
Clinical Research at the Binter Center

Have you been diagnosed with Parkinson’s Disease and also experience irregular bowel movements or constipation?

Dr. Lisa Deuel is leading a 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

If you have questions about research opportunities, please contact our Research Coordinators:
Emily Houston, (802) 656-8974 Emily.houston@med.uvm.edu
Katherine Chan, (802) 847-1597 Katherine.chan@uvmhealth.org

Inaugural Annual Ashok Gupta Memorial Lecture in Parkinsonian Disorders

The Frederick C. Binter Center for Parkinson’s Disease and Movement Disorders hosted the inaugural Annual Ashok Gupta Memorial Lecture in Parkinsonian Disorders on April 21st Friday 2022 from 12 to 1pm ET at the Davis Auditorium in the University of Vermont Medical Center and virtually through Zoom.

Dr. Stanley Fahn, MD, was the visiting speaker for the inaugural lecture and the title of his talk was “The Revolutionary Treatment of Parkinson’s Disease That Almost Got Away: The Levodopa Story”. The lecture was attended by up to 150 people, including the Binter Center’s patients and their family members, and members of department of Neurological Sciences at the University of Vermont.

This memorial lecture was supported by the Ashok Gupta Foundation for Parkinsonian Disorders, and it is expected to be held annually in the month of April.

A recording of this year’s inaugural lecture can be viewed at this link: bit.ly/2022aagmlpd

From left to right: Dr. Lisa Deuel, Dr. Deepak Gupta, Dr. Fahn, Dr. Robert Hamill, Dr. James Boyd, after the lecture on April 21st, 2022
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.

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
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.