

University of Vermont MEDICAL CENTER

Binter Center Newsletter Fall 2018

IN THIS ISSUE

A Practical Overview of Parkinson's Disease Treatment [pg. 1 – 4]

Staff Spotlight [pg. 1]

World Parkinson Congress [pg. 5]

VT Team Hope Walk [pg. 6]

Huntington's Education Day [pg. 7]

PushBack Volunteers [pg. 8]

APDA New England Regional Conference [pg. 9]

Vermont Adaptive Ski & Sports [pg. 9]

Clinical Trials [pg. 10-11]

Movement for Parkinson's [pg. 12]

Other Exercise, Support and Education Opportunities [pg. 13-18]

The Robert W. Hamill Respite Care Program [pg. 19]

Calendar of Events [pg. 20-23]



TOP STORY



A Practical Overview of Parkinson's Disease Treatments: Part 1 of 3—Early Motor Features Deepak Gupta, MD

Movement disorders are a group of neurological disorders characterized by abnormalities in the control of movements of different body parts and/or the whole body. These can include:

- Rhythmic shaking (tremor),
- Slowness of movements (bradykinesia), with or without reduced amplitude (hypokinesia) and interruptions,
- Stiffness (rigidity),
- Excessive contraction of muscles (dystonia),
- Incoordination (ataxia),
- Dance-like movements (chorea),

Jerky movements (ballism).

• Writhing movements (athetosis), or

(continued on page 2)

Staff Spotlight: Welcome Deepak Gupta, MD!

The Binter Center is excited to welcome Dr. Deepak K. Gupta to our team beginning in July 2018. Dr. Gupta completed medical school at University of Delhi, India, and decided very early on to specialize in Movement Disorders from after personal experiences with a close family member with Parkinson's disease (PD).

He finished his Neurology residency training, including a research track focused in PD, at University Hospitals Cleveland Medical Center, Case Western Reserve University. He went on to complete postdoctoral fellowship training in Movement Disorders, with additional clinical focus in dementia, at the Neurological Institute of New York, Columbia University. Dr. Gupta conducts translational research in PD and related neurodegenerative disorders, along with education research in Neurology graduate medical education.

He is excited to have moved to Vermont with his wife, Rashmi Gupta, who is a Business Analyst, and their three-year -old daughter.

Treatment of PD cont.

Parkinson's disease (PD) is the most common movement disorder and constitutes close to 75% of all patients seen in a typical movement disorders clinic. Other movement disorders include essential tremor (the most common movement disorder in adults), Tourette's syndrome/Tic disorders (the most common movement disorder in children), dystonias, normal pressure hydrocephalus, psychogenic/functional movement disorder, restless leg syndrome, ataxias, atypical parkinsonism, tardive syndromes, post-traumatic movement disorder, and Huntington's disease.

PD is classically defined based on motor symptoms, namely the presence of bradykinesia with rigidity and/or resting tremor. Postural and gait instability is also typically included in the motor definition of PD, however these symptoms don't usually emerge until later in the disease course. Other advanced motor features include:

- Motor fluctuations (on-off phenomenon),
- Dyskinesia,
- Drooling (sialorrhea),
- Dystonia, and
- Freezing of gait (FOG).

Although PD has been historically considered as a movement disorder, patients frequently have one or more of the following non-motor clinical features:

- Cognitive impairment (dementia),
- Mood changes including anxiety, depression, and apathy,
- Autonomic changes which can include low standing blood pressure, constipation, urinary problems, and/or abnormal sweating,
- Sleep issues including REM Sleep Behavior Disorder (RBD), sleep fragmentation, excessive daytime sleepiness,
- Fatigue, and
- Pain.

Before delving into specific details of various treatments below, it is helpful to understand an important distinction between *symptomatic* versus *disease-modifying* therapies. Symptomatic therapies alleviate symptoms with no effect on the underlying cause of the disease while disease-modifying therapies slow down, stop, and/or reverse the underlying disease; these can also be called neuroprotective therapies. For example, treating an ear infection with Tylenol would be an example of symptomatic treatment, while treatment with an antibiotic would be considered a disease-modifying treatment.

Finally, treatments can also be divided into the following three categories: approved by the Food and Drug Administration (FDA) and/or insurance companies for clinical use, typically based on results of randomized clinical trials/research studies; off-label use a drug developed and approved for an alternative condition, but used by the physician based on their clinical judgement and supportive evidence for use in PD; and experimental use in animal and/or human research studies and not available for clinical use. It is important to note that virtually all of the currently available treatments for PD, either approved or off-label, are symptomatic. Many of the experimental drugs currently in clinical trials are expected to provide neuroprotective options in the future.

Treatments for PD can be discussed in two categories: pharmacological (levodopa and other dopamine replacement drugs and non-dopamine directed drugs), and non-pharmacological, including rehabilitative therapies and surgical procedures. Another way to discuss treatment options for PD is by motor features (early and advanced) and non-motor features. The following content in this article, the first of a three-part series, will aim to cover treatment for early motor features, while the subsequent two articles will focus on advanced motor and non-motor features, respectively.

Treatment of PD cont.

1. Levodopa-based Pharmacological treatment:

Levodopa is one of the oldest and most successful symptomatic treatments for PD. It is based on the basic principle that dopamine-producing neurons are preferentially affected in PD. Dopamine is the principle chemical (neurotransmitter) of the brain's motor control system (basal ganglia), and its deficiency in PD has been proposed to be the underlying basis of several of the motor symptoms in PD, with the notable exception of tremor. Levodopa is a precursor of dopamine and is currently available in oral pill and infusion pump form. Clinical trials are underway for inhaled and under the skin pump formulations of levodopa.

Carbidopa is generally combined with levodopa to reduce to reduce the conversion of levodopa into dopamine outside of the brain, and thus maximize its availability inside the brain while minimizing side effects. Sinemet was the original brand name for the combined formulation of carbidopa-levodopa and is commonly used synonymously by physicians and pharmacists. Carbidopa is combined with levodopa in a single tablet formulation (e.g., Sinemet 25-100 mg, 50-200 mg, and 10-100 mg). In addition to the usual immediate release tablet, an extended release/sustained release tablet is also available as Sinemet CR, which allows slow release in the gastrointestinal tract. Finally, an orally disintegrating tablet (Parcopa) is also available, which can be used in situations where swallowing may be difficult or not possible.

Levodopa does not carry the risk of major side effects or interactions with other drugs and is generally given at an initial standard dose of 25-100 mg three times a day. However, this dose is achieved gradually to avoid potential side-effects of dose-related nausea and/or vomiting, sleepiness, dizziness, and/or a drop in blood pressure. For the same reasons, it is recommended to take levodopa with or immediately after food in the beginning. However, Sinemet should be generally taken either one hour before (preferably) or about two hours after food, as protein in food can interfere with its absorption in the small intestine. As a last resort, a separate tablet of carbidopa can be added to Sinemet to further reduce these temporary side-effects. Once the patient is used to taking a stable dose for few weeks, levodopa should be generally taken either one hour before (preferably) or about two hours after food, as protein in food can interfere with its absorption in the small intestine and with entry into the brain.

Levodopa provides robust improvement in motor symptoms for virtually all PD patients, with tremor being the most variable in terms of amount of improvement among different people. A commonly perceived myth about levodopa is that its use should be delayed as long as possible since it stops working after few years. In fact, this is not true at all. Rather, it is the progression of disease, which requires higher doses and/or frequency of administration, rather than levodopa losing its efficacy. A common reason to delay initiation of levodopa in favor of other PD medications (see below) is to delay emergence of advanced motor features that can appear with larger doses and longer exposure to levodopa, specifically motor fluctuations and dyskinesia.

2. Non-levodopa based Pharmacological Treatments:

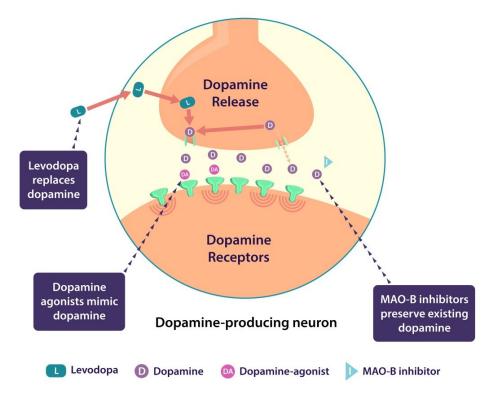
i. Dopamine agonists (DA) include drugs which bind to dopamine receptors in the brain and elicit a biological response similar to dopamine. DA are almost as effective as levodopa in early PD but have more side effects, such as impulse control disorders (compulsive eating, gambling, buying, and hypersexuality), weight gain, and sleep attacks.

Most neurologists use DA as first line of treatment in younger patients with the goal of delaying use of levodopa and avoid DA in patients older than 70 and those patients with cognitive impairment or with a history of addictions. Oral DA, namely pramipexole (Mirapex) and ropinirole (Requip), are available in immediate release (three times a day) and extended release (once a day) formulations. A once-daily skin patch formulation, namely rotigotine (Neupro), is also available. Apomorphine (Apokyn) is a rapidly acting, however short duration, injectable formulation available as a rescue treatment for sudden off-periods.

(continued on page 4)

Treatment of PD cont.

- ii. Monoamine oxidase type B (MAO-B) inhibitors selectively target an enzyme in the brain cells which break down dopapmine, and this helps prolong the availability of the brain's own dopamine. These medications include selegiline, rasagiline (Azilect), and newly approved safinamide (Xadago). These treatments provide only modest symptomatic benefit and have minimal side effects, the most common of which is insomnia (especially with selegiline), which can be minimized by taking the pill in morning. Data from research studies suggests that MAO-B inhibitors may have a disease-modifying effect, however the evidence is not yet robust. Accordingly, several neurologists tend to use MAO-B inhibitors as an initial treatment in newly diagnosed patients, especially those with no significant need of other symptomatic treatments.
- iii. Anticholinergics are an older group of medications used for a variety of neurological and non-neurological problems.
 In the context of PD, Trihexyphenidyl (Artane) and benztropine (Cogentin) are occasionally used for management of tremor or dystonia in young PD patients, but these are best avoided in most patients due to frequent side effects.



3. Rehabilitative Therapies:

Physical therapy (PT) and speech therapy (ST) should be utilized in treatment of early motor features, specifically for the development of a patient-centered exercise program and for improving low volume of speech (hypophonia), respectively. In the last few years, several PD-specific programs have become available, most of which are available in Vermont:

- Push Back at Parkinson's Disease exercise program (developed by the Binter Center and covered in our Winter 2017-18 newsletter),
- Dance for PD,
- Rock Steady Boxing,
- LSVT LOUD for speech therapy, and
- LSVT BIG for physical and occupational therapies.

Stay tuned for the next part of the series in our next newsletter: Part 2: Advanced Motor Features.

4





Vermont Team Hope Walk

Saturday, September 29, 2019

University of Vermont at the U-Oval Burlington, VT

Registration, raffle, food, & music begins at 9:00am Walk begins at 10:00am

> Daniel Dulude dbshadow@comcast.net or (802) 734-3849

REGISTER TODAY!

www.hdsa.org/thwvermont

Sponsored By



HDSA.org

(800)345-HDSA



Huntington's Disease Education Day

Immediately following the HOPE WALK

Saturday, Sept 29, 2018 12:00-3:30

UVM Medical Center McClure Lobby Conference Room Burlington, Vermont

	AGENDA
9:00- 11:45	Hope Walk at UVM University Height Oval
11:45	Hope Walk to Conference Room
12:00	Lunch
12:30	Clinical Trials and Research Update James T. Boyd, MD
1:30	HD Advocacy Lori P. McKenna, LICSW
1:45	Caregiving Needs & Communication Lori P. McKenna, LICSW
2:15	Behavioral Challenges in HD Suzanne Kennedy, MD
3:15	Closing Comments and Evaluations

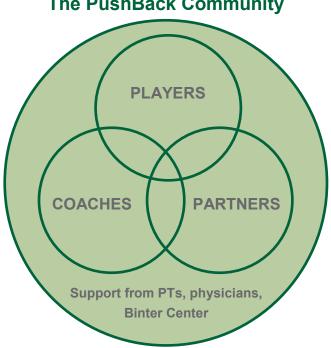
This event is free of charge but **REGISTRATION IS REQUIRED by September 16**

Please visit <u>https://hdsa.donordrive.com/event/1545</u> or call (802) 847-4334 to sign up.

This program is funded by the Huntington's Disease Society of America through an unrestricted educational grant from Teva.

Volunteers Needed for PushBack at Parkinson's Disease Exercise Program

PushBack at Parkinson's Disease – or simply "PushBack" – is a great collaboration between the Binter Center, physical therapists, community gyms, Vermont Adaptive Ski and Sports, and volunteer partners. PT leaders Maggie Holt and Parminder Padgett train community partners in an exercise program that targets PD problems and allows people to PushBack with an intensity that can make a difference.



The PushBack Community

We need YOU in order to grow!

If you would like to be trained as a volunteer partner to help support people with Parkinson's exercise...

-OR-

If you know of a local gym or local exercise practitioner who would be interested in bringing PushBack to your community...

Please call (802) 847-0522 or email margaret.holt@uvmhealth.org

We are especially in need of volunteers for existing programs in the Burlington area and newly formed programs in Central Vermont.

Have PD and want to know how to participate in the PushBack program? See page 9!







Be Active with Vermont Adaptive!

Vermont Adaptive Ski and Sports is a nationally recognized organization that empowers people of all abilities through inclusive sports and recreational programming regardless of ability to pay. In addition to sports, year round programming options integrate environmental, holistic wellness, and competitive training philosophies for people of all ages with cognitive, developmental, physical and emotional disabilities. The organization also has an active veterans program, serving all veterans with disabilities.

In the summer, the organization provides lessons and outings statewide including in Chittenden County and the Burlington Waterfront as well as throughout the Waterbury/ Montpelier area and in central and southern Vermont. Sports and activities include tandem biking, hand-cycling, mountain biking, hiking, canoeing, kayaking, stand-up paddle boarding, sailing, horseback riding, rock climbing, Beeper baseball, wellness programs, environmental programs and more. In the winter, alpine and Nordic skiing, snowshoeing, indoor rock climbing and holistic programs are offered at Pico Mountain, Killington; Sugarbush Resort, Waitsfield; and Bolton Valley Ski Area, Bolton. Other locations are available upon request.

For more information visit <u>www.vermontadaptive.org</u>. For specific program information, contact program coordinator Kelly Walsh at (802) 786-4991 ext. 27 or <u>truenorth@vermontadaptive.org</u>.



APDA NEW ENGLAND CONFERENCE

AMERICAN PARKINSON DISEASE ASSOCIATION

Strength in optimism. Hope in progress.

APDA New England Regional Conference

Sunday, October 14 - Monday, October 15, 2018

Holiday Inn - Mansfield, MA

The Connecticut, Massachusetts, Rhode Island, and Vermont Chapters and Information & Referral Centers of the APDA will bring this very special two-day educational event to Mansfield, MA. See familiar faces and meet new friends as you learn more about a spectrum of Parkinson's topics. The first night will be topped off by a Sunday Social where you can meet and greet, dance, and have fun!

This year's topics will include an update on research as well as information on Deep Brain Stimulation (DBS), new therapies for motor fluctuations, medical management of low blood pressure, and much more. Exhibitors will be available to inform you on resources available to you throughout New England.

Pre-registration is required.

Visit <u>www.apdama.org</u> for complete details and online registration or call (800) 651-8466.

UVM Medical Center Parkinson's Disease Clinical Trials

PASADENA

A Study to Evaluate the Efficacy of RO7046015 in Participants With Early Parkinson's Disease (PASADENA)

This multicenter, randomized, double-blind, placebo-controlled, Phase 2 study will evaluate the efficacy of intravenous RO7046015 versus placebo over 52 weeks in participants with early Parkinson's Disease (PD) who are untreated or treated with monoamine oxidase B (MAO-B) inhibitors since baseline. The study will consist of 2 parts: a 52-week, double -blind, placebo-controlled treatment period (Part 1) after which eligible participants will continue into an all-participants-on-treatment blinded dose extension for an additional 52 weeks (Part 2).

This study is underway but is no longer recruiting at our location.

iNDiGO

A multicenter, randomized, double-blind, placebo controlled, parallel group clinical study investigating the efficacy, tolerability, and safety of continuous subcutaneous ND0612 infusion Given as adjunct treatment to oral levOdopa in patients with Parkinson's Disease with motor fluctuations (iNDiGO)

We are conducting a research study that is evaluating an investigational Parkinson's disease treatment that uses a pump system to deliver a continuous infusion of an investigational medication. We want to learn more about the safety and effectiveness of this investigational treatment and medication.

To pre-qualify for this study, you must be:

- At least 30 years of age
- Diagnosed with Parkinson's disease



- Experiencing motor fluctuations and an average of at least 2 hours daily in the "OFF" state during waking hours
- Taking stable treatment with at least 4 daily doses of levodopa/carbidopa (or at least 3 daily doses of Rytary)
- Stable on your anti-Parkinson's disease medication for at least 28 days before the study

Study recruitment will open Fall/Winter 2018.

SURE-PD3

A randomized, double-blind, placebo-controlled trial of urate elevating Inosine treatment to slow the clinical decline in early Parkinson's disease.

Previous studies have shown increased urate levels to be associated with slower rates of PD progression. Urate is now being considered as a neuroprotective agent for PD, and the study drug, inosine, will be used to bring urate levels up to a moderate level.

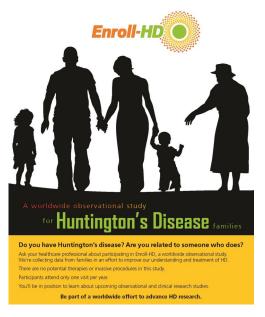
The main objective of this study is to determine if oral inosine will slow the clinical decline in early PD, with a 2 year treatment dose that moderately elevates serum urate.

You may be eligible to participate if you:

- Have a clinical diagnosis of PD made within 3 years to the first visit (screening visit)
- Are at least 30 years of age
- Are not requiring dopaminergic therapy
- Have a non-fasting serum urate level of ≤ 5.7 mg/dL at the first visit (screening visit) This study is underway but no longer currently recruiting.



UVM Medical Center Huntington's Disease Clinical Trials



Enroll-HD

Enroll-HD is an open-ended, prospective study, where participants will be asked to complete annual study visits. This will allow researchers to improve our understanding of the disease spectrum, to promote the development of evidence-based guidelines, and to improve health care outcomes and to develop beneficial treatments.

This study is currently enrolling individuals who have Huntington's disease, as well as individuals who are unsure if they are carriers of the HD gene expansion mutation, those who are related to someone with HD, and community controls (no relation to someone with HD, nor a family history of HD)

SIGNAL

A Phase 2, multi-center, randomized, double-blind, placebo controlled study in subjects with late prodromal and early manifest Huntington disease (HD) to assess the safety, tolerability, pharmacokinetics, and efficacy of VX15/2503

In this study, researchers are looking at a monoclonal antibody, VX15/2503, as a potential treatment for HD. This monoclonal antibody is a class of drug that binds to a molecule, and may block it from causing inflammation in the brain of those with HD. It may specifically protect against the inflammation that has been shown to affect thinking, movement and behaviors in those with HD.

Call for enrollment information.





UVM Medical Center Essential Tremor Clinical Trials

Are you currently taking Primidone for Essential Tremor? Would you like to help us better understand how Primidone effects tremor reduction or severity?

In this study, participants that are currently taking primidone will be asked to bring their daily dose to the clinic to be administered in a controlled clinic setting. Dr. Boyd and his study staff will monitor changes in tremor and blood levels of the medication. This study will require two visits to the Movement Disorders Clinic at the University of Vermont Medical Center, 1 South Prospect Street.

This study is currently recruiting.

For information or questions about participation in any of our clinical trials, please contact Emily Houston, Research Coordinator at (802) 656-8974 or Emily.Houston@med.uvm.edu

Movement for Parkinson's Classes

Offered for people with Parkinson's disease and their care partners, this dance class is designed to engage participants' minds and bodies through many styles of dance, while exploring stretching, muscle strengthening, postural stability, and rhythm through instruction and energizing music. The class is offered in a relaxed social environment that emphasizes enjoyment, fun, and creativity, with an eye towards connecting with the community.

No dance experience required.

Burlington Flynn Arts, 153 Main St. Monday's AND Wednesday's, 10-11:30am Beginning week of Sept 10 Visit <u>www.flynncenter.org</u> or call (802) 652-4537 FREE Montpelier Montpelier Senior Activity Center, 58 Barre St. Thursday's, 10-11:30am Beginning Sept 13 Call (802) 223-2518 to register Cost: \$25 member, \$35 public

Saint Albans Homestead at Pillsbury Manor, 3 Harborview Dr. Every 3rd Friday beginning Sept 21, 10-11 am FREE

Visit <u>www.movementforparkinsons.com</u> for the most up-to-date information!

Classes taught by M Sara McMahon, MA, FlynnArts Faculty member, who is a professional movement performer and educator trained in the Dance for PD[®] method.

For information about any of these classes, please contact Sara McMahon at (802) 881-9673 or <u>movement.for.parkinsons@gmail.com</u>

Exercise, Education and Support Opportunities

Dance: Moving Better, Living Better

For generations, dance was held in the center of social gatherings of all kinds. Dance provided the opportunity to develop incredibly valuable skills such as sequencing movement, being precise in expressivity and rhythm, and engaging socially through movement. All of these qualities are critically important in sharpening neuro-pathways of the brain that enhance our quality of life, no matter what our age. These learning challenges, when taught in a group with good music, can be irresistible! And, these classes provide all the good things other movement classes offer, such as building strength, stamina, flexibility and postural stability – so you're getting your workout.

Liesje Smith, dancer, performer and certified Rolfer, is an inspiring and experienced teacher who brings an opportunity for you to develop the above skills in a fun and inspiring atmosphere. She can be contacted at <u>liesjesmith2@gmail.com</u> or (802) 355-1277.

<u>Charlotte Senior Center - 125 Ferry Road, Charlotte, VT</u> Friday's from 9:30–10:30 Call for specific session dates. Cost: \$60 per session. Registration necessary. Call (802) 425-6345.

Keep Moving With Parkinson's



The Dee Physical Therapy Wellness Program is offering a 6week series exercise class designed specifically for individuals with Parkinson's Disease. The class is taught by Laurel Lakey, a Physical Therapist Assistant who has a BFA in Dance. Exercises emphasize balance training, posture, flexibility and strength and are performed in both seated and

standing positions alongside musical selections. Participants may bring along one guest such as a significant other, family member, or caregiver to join as well.

For questions and to register, please call Dee Physical Therapy in Shelburne at 802-985-4440 and ask for Laurel Lakey, or email her at <u>laurellakey@deept.com.</u>

When:	CALL FOR SPECIFIC SESSION DATES Thursday's from 1:00-2:00pm,
Where:	Aerobics Room in the Shelburne Field House - 166 Athletic Drive, Shelburne
Cost:	\$60.00 for 6 classes (covers you plus one guest)

Please note: This class is appropriate for individuals who are able to ambulate independently. For those who require assistance with ambulation but are interested in taking part, please contact the instructor.



Boston Educational Meeting Sunday, October 28, 2018, 1:00-4:00pm

Boston Marriott Newton 2345 Commonwealth Avenue, Newton, MA 02466

Join the DMRF to learn about dystonia and meet others in the community. This is a <u>free</u> meeting and advance registration is requested.

Visit <u>www.dystonia-foundation.org</u> or call 312-755-0198 for more information.

Huntington's Disease Support Groups

HDSA Centers of Excellence provide vital information, support, and information to those affected by HD and their families. Support groups can be one way to help you make connections with others who may be experiencing similar challenges.

Caregivers, family members, loved ones, and people with HD are all welcome.

Vermont Nev

When: 2nd Tuesday of every month, 5:30-7:00 P.M.

Where: UVM Medical Center - Fanny Allen Campus, Dunbar Room, 790 College Parkway, Colchester, VT

Parking is free.

Contact: Lori McKenna, (802) 847-1111 or Lori.McKenna@UVMHealth.org

New Hampshire

When: 1st Wednesday of every month, 6:00-7:30 P.M.

Where: Dartmouth-Hitchcock Medical Center, Fuller Board Room, 1 Medical Center Drive, Lebanon, NH

Follow signs to DHMC's Main Entrance parking lot. (Parking is free.) Confirm location at info desk in Rotunda.

Contact: Diane L. Sherman, (603) 653-6672 or <u>Diane.L.Sherman@hitchcock.org</u>

HUNTINGTON'S DISEASE SOCIETY OF AMERICA ANNUAL CONVENTION



Couldn't Attend? Watch Online!

Convention content is archived on the HDSA website:

http://hdsa.org/about-hdsa/annualconvention/2018-2/

Save the Date for 2019! June 27-29 in Boston, Massachusetts

ADAPTIVE CHAIR YOGA

SANGHA STUDIO NORTH 237 N. WINOOSKI AVE., BURLINGTON VT



Sponsored by the MS Program at the UVM Medical Center

University of Vermont MEDICAL CENTER



FREE! JOIN US: 2:00-3:15PM FIRST AND THIRD THURSDAYS OF EVERY MONTH

perfect for yoga beginners! open to anyone with multiple sclerosis or parkinson's disease great for strength, balance, breathing, and relaxation accessible parking available on street and in parking garage

For more information and questions: email us at info@sanghastudio.org or visit sanghastudio..org

The Parkinson's Pantomime Project (Mime Over Matter!)

For people with Parkinson's and other movement disorders, basic mime technique is taught as a method for helping cope with movement limitations. The classes explore visualization, articulation of gesture, and creative use of imagery and space. Circus games are geared for delightful fun: we play with manual dexterity (juggling), coordination, postural awareness, and development of reflexes. We conduct music, play circus games, and study the mime principles of Marcel Marceau in order to facilitate daily actions. Those who wish can join The PD Players a Parkinson's performance troupe in a show at the end of the session! Fun, with a purpose!

Classes are taught by Rob Mermin (right), founder of Circus Smirkus. He trained with renowned mime Marcel Marceau (left) before embarking on a 40-year career in the theater and circus world. Rob lives in Montpelier.

Saturdays, 10:30-12:00 Montpelier Senior Activities Center, 58 Barre Street \$20 members/\$30 public (ages 50+) Contact (802) 223-2518 or <u>msac@montpelier-vt.org</u> to register

International Essential Tremor Foundation

Essential Tremor (ET) is a neurological disorder that can impact individuals both physically and psychologically. The condition causes rhythmic trembling of the hands, head, legs, or voice, and can occur in people of any age, gender, or race. More people are diagnosed with ET than any other movement disorder - an estimated 10 million in the United States alone. While no cure has been found to date, medications and surgical treatments can help control



tremor in many patients.

The IETF is a 501(c)(3) non-profit organization that funds research to find the cause of essential tremor that leads to treatments and a cure, increases awareness, and provides educational materials, tools, and support for healthcare providers, the public, and those affected by ET. Visit <u>www.EssentialTremor.org</u> or call (888) 387-3667 for information and resources.

The Vermont Massage Clinic is a community-based massage center located in Essex, VT that is designed to offer affordable and sustainable massage and Chinese medicine treatments.

Co-founders Julie Viau and Caitlin Perry have extensive training and education in bodywork and Chinese medicine studies, skills they use to help people overcome illnesses and imbalances. They use a



combination of touch, nutrition counseling, emotional support, acupressure, and eastern medicine modalities to help their clients seek out overall well-being. Chinese medicine and massage can be used to help lessen the severity of symptoms associated with Parkinson's disease (PD). Many times, lessening suffering by only 20-30% can make life tolerable for an individual coping with chronic pain and immobility.

Part of the mission of the Vermont Massage Clinic is to offer **free and affordable care to the Parkinson's Community** through a voucher program that supports care for people with PD. Vouchers are given on a first come, first serve basis, and once a client is enrolled in the voucher program, they can continue to come each month. The non-voucher rate for people with PD is only \$40.00 for 60 minutes.

For more information about this unique, community-supported program, please visit The Vermont Massage Clinic's website at <u>www.vtmassageclinic.com</u> or call (802) 324-3931.

PushBack at Parkinson's Disease Exercise Program

PushBack at Parkinson's Disease - or "PushBack" - is an exercise program for people with PD. It is informed by current evidence; it provides a supportive environment; it emphasizes intensity of exercise; and it is adaptable individual levels of ability. Most importantly, it's FUN!

CHITTENDEN COUNTY

REGISTRATION INFORMATION

STEP 1: These classes <u>require</u> a screening by a physical therapist prior to participation. Schedule time with a local PT by calling UVM Medical Center Rehab Therapies at (802) 847-1902. These appointments are billable to your insurance.

STEP 2: Decide with the PT when you are ready to start a class. When you are, then call one of the gyms below, sign up, and follow their instructions.

COMBAT FITNESS

276 East Allen Street, Winooski (802) 655-5425 Tuesdays and Thursdays October 9 - December 13 2:00-3:00 or 3:00-4:00 \$200 for 10-week session (20 classes)

HAMMERFIT

21 Essex Way #115, Essex Junction (802) 878-0444 Wednesdays and Fridays Classes Ongoing 2:00-3:00 \$10.00 per class

CENTRAL VERMONT

REGISTRATION INFORMATION

STEP 1: These classes require a screening by a physical therapist prior to participation. Schedule time with a local PT by calling one of the locations listed below. These appointments are billable to your insurance.

STEP 2: Decide with the PT when you are ready to start a class. When you are, then contact the a gym location, sign up, and follow their instructions.

CVMC REHABILITATION

1311 Barre-Montpelier Road, Berlin (802) 371-4242 - ask for Larissa or Emily Mondays and Wednesdays August 27 - November 14 1:00-2:00 No cost for 12-week session (24 classes)

REHABGYM

219 N. Main Street, Barre Suite 103 (802) 479-4000 Tuesdays and Thursdays August 7 - October 25 2:00-3:00 \$120 for 12-week session (24 classes)

QUESTIONS AND SCHOLARSHIPS

Cost should not be a barrier to your participation! Scholarships are available if you are unable to afford the cost of the classes. If you have questions or need to apply for scholarship funding, please contact Charlotte Gowen, Binter Center Program Coordinator, at (802) 847-4334 or <u>Charlotte.Gowen@uvmhealth.org</u>.

Parkinson's Disease Support and Outreach Groups

Addison County, Last Thursday, 10-11:30 am Residence at Otter Creek, 350 Lodge Road, Middlebury Contact: APDA, (802) 847-3366, apdavermont@apdaparkinson.org

Brattleboro, 2nd Saturday, 10:00-11:30 Brattleboro Memorial Hospital - Main Board Room Contact: Jim Devincentis, (802) 258-7077, werdevo12@gmail.com



Burlington, 2nd Wednesday, 1-2:30 pm Residence at Shelburne Bay, 185 Pine Haven Shores Road, Shelburne – East Bldg Contact: APDA, (802) 847-3366, apdavermont@apdaparkinson.org

Central Vermont, Saturdays, once per month, 1-3 pm Westview Meadows at Montpelier, 171 Westview Meadows Road, Montpelier Contact: Shery Mead, (802) 540-8153, <u>sherymead@gmail.com</u>

St. Albans, 2nd Tuesday, 10-11:30 am Pillsbury Homestead Conference Room, 3 Harbor View Drive, St. Albans Contact: Pat Rugg, (802) 524-5520, <u>patrica_rugg18@comcast.net</u>

St. Johnsbury, 3rd Friday, 10:30 am-12 pm Northeastern Vermont Regional Hospital Contact: Brendan Hadash, (802) 748-8074, <u>bhadash@sover.net</u>

New York: Potsdam, 3rd Wednesday, 2:00 Clarkson University, Clarkson Hall, 59 Main St., Potsdam – follow signs to the room Contact: Rebecca Martin, (315) 268-1652, <u>rmartin@clarkson.edu</u>

Don't see a support group in your area? You can start one! Contact Charlotte Gowen, Program Coordinator, at (802) 847-4334 or <u>Charlotte.Gowen@UVMHealth.org</u>

The Robert W. Hamill, MD Respite Care Program

About the Program

The Robert W. Hamill, MD Respite Care Program was initiated by the Vermont Chapter of the American Parkinson Disease Association (APDA) in 2009 to help ease the burden on those who care for people with Parkinson's disease. The program continues to be supported by ongoing fundraising efforts and donations to the Vermont Chapter.

What is the Program For?

The APDA is very aware of the enormous contribution family care partners offer every day to people with Parkinson's disease. We also know caregivers cannot give unendingly without some time and space to recharge themselves. Sometimes, a care partner is not comfortable leaving a family member alone. This program is designed to help pay for short term home care to supplement the care usually provided by family members. This allows the family caregivers to know their loved one is safe in the home while they are gone.

Eligibility Guidelines

- The person with PD and the caregiver must live together in Vermont.
- The APDA Vermont Chapter must receive a note from the physician confirming the diagnosis of PD.
- There are no income guidelines.

How Does it Work?

The APDA Vermont Chapter has contracted with home care agencies and adult day programs throughout the state. To arrange for respite care, simply follow the steps below:

- Contact the APDA Vermont Chapter at (802) 847-3366 or apdavermont@apdaparkinson.org.
- Have the physician who cares for the person with PD send a note confirming the diagnosis of PD and the need for respite care.
- Contact a local home care agency or adult day program to arrange care. We are happy to provide a list but we cannot make recommendations.
- A voucher is provided for 8 hours of respite care. Care can be provided in any increment. We will send the vouchers directly to your provider of choice.
- The agency will then submit an invoice to us for payment along with the signed voucher.
- The maximum number of hours allowed for payment is 8 per month.

AMERICAN PARKINSON DISEASE ASSOCIATION

VERMONT CHAPTER

Strength in optimism. Hope in progress.

Sept	September sunday monday tues	Per	Movement Classes Support Groups Educational Opportunities Other Events WEDNESDAY	liies THURSDAY	THE University of Vermont M E D I C A L C E N T E R FRIDAY SATURDAY
**Calendar items are subject to change at any time. Contact the group leader before attending any event.					
2	S	4	5 NH HD Support Group, 6-00-7-30	6	7
9	10	11	12	13	14
	Movement for PD, Flynn Arts, 10:00-11:30	St. Albans PD Support Group, 10:00-11:30	Movement for PD, Flynn Arts, 10:00-11:30	Movement for PD, Montpelier Senior Ctr,	
		VT HD Support Group, 5:30-7:00	Burlington PD Support Group, 1:00-2:30	10:00-11:30	
16	17 Movement for PD, Flynn Arts. 10:00-11:30	18	19 Movement for PD, Flynn Arts. 10:00-11:30	20 Movement for PD, Montpelier Senior Ctr.	21 Movement for PD, Saint Albans, 10:00-11:15
				10:00-11:30	St. Johnsbury PD Support Group, 10:30- 12:00
23/30	24	25	26	27	28
	Movement for PD, Flynn Arts, 10:00-11:30		Movement for PD, Flynn Arts, 10:00-11:30	Movement for PD, Montpelier Senior Ctr, 10:00-11:30	Addison Co. PD Support Group, 10:00-11:30

Octo	ctober		Movement Classes Support Groups Educational Opportunities Other Events	ities	MEDICA	MEDICAL CENTER
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
**Calendar items are subject to change at any time. Contact the group leader before attending any event.	4	Ν	3 Movement for PD, Flynn Arts, 10:00-11:30 NH HD Support Group, 6:00-7:30	4 Movement for PD, Montpelier Senior Ctr, 10:00-11:30	IJ	6 Mime Over Matter 10:30-12:00 Young Onset PD Support Group, 1:00-3:00
7	8 Movement for PD, Flynn Arts, 10:00-11:30	9 St. Albans PD Support Group, 10:00-11:30 VT HD Support Group, 5:30-7:00	10 Movement for PD, Flynn Arts, 10:00-11:30 Burlington PD Support Group, 1:00-2:30	11 Movement for PD, Montpelier Senior Ctr, 10:00-11:30	12	13 Mime Over Matter 10:30-12:00 Brattleboro PD Support Group, 6:00
14 New England APDA Conference, Mansfield, MA	15 Movement for PD, Flynn Arts, 10:00-11:30 New England APDA Conference, Mansfield, MA	16	17 Movement for PD, Flynn Arts, 10:00-11:30	18 Movement for PD, Montpelier Senior Ctr, 10:00-11:30	19Movement for PD, SaintAlbans, 10:00-11:15St. Johnsbury PDSupport Group, 10:30-12:00	20 Mime Over Matter 10:30-12:00
21	22 Movement for PD, Flynn Arts, 10:00-11:30	23	24 Movement for PD, Flynn Arts, 10:00-11:30	25 Movement for PD, Montpelier Senior Ctr, 10:00-11:30 Addison Co. PD Support Group, 10:00-11:30	26	27 Mime Over Matter 10:30-12:00
28 Dystonia Education Meeting, Boston	29 Movement for PD, Flynn Arts, 10:00-11:30	30	31 Movement for PD, Flynn Arts, 10:00-11:30			

25	18	11	4		SUNDAY
26 Movement for PD, Flynn Arts, 10:00-11:30	19 Movement for PD, Flynn Arts, 10:00-11:30	12 Movement for PD, Flynn Arts, 10:00-11:30	5 Movement for PD, Flynn Arts, 10:00-11:30		MONDAY
27	20	13 St. Albans PD Support Group, 10:00-11:30 VT HD Support Group, 5:30-7:00	6		TUESDAY
28 Movement for PD, Flynn Arts, 10:00-11:30	21 Movement for PD, Flynn Arts, 10:00-11:30	14 Movement for PD, Flynn Arts, 10:00-11:30 Burlington PD Support Group, 1:00-2:30	7 Movement for PD, Flynn Arts, 10:00-11:30 NH HD Support Group, 6:00-7:30		WEDNESDAY
29 Movement for PD, Montpelier Senior Ctr, 10:00-11:30 Addison Co. PD Support Group, 10:00-11:30	22	15 Movement for PD, Montpelier Senior Ctr, 10:00-11:30	8 Movement for PD, Montpelier Senior Ctr, 10:00-11:30	1 Movement for PD, Montpelier Senior Ctr, 10:00-11:30	THURSDAY
30	23	16Movement for PD, Saint Albans, 10:00-11:15St. Johnsbury PD Support Group, 10:30- 12:00	9	2	FRIDAY
**Calendar items are subject to change at any time. Contact the group leader before attending any event.	24 Mime Over Matter 10:30-12:00	17 Mime Over Matter 10:30-12:00	10 Mime Over Matter 10:30-12:00 Brattleboro PD Support Group, 6:00	3 Mime Over Matter 10:30-12:00 Young Onset PD Support Group, 1:00-3:00	SATURDAY

November

Support Groups Educational Opportunities

MEDICAL CENTER

Movement Classes

Other Events

23	16	9	2	**Calendar items are subject to change at any time. Contact the group leader before attending any event.	SUNDAY	Dece
24	17	10 Movement for PD, Flynn Arts, 10:00-11:30	3 Movement for PD, Flynn Arts, 10:00-11:30		MONDAY	ecember
25	18	11 St. Albans PD Support Group, 10:00-11:30 VT HD Support Group, 5:30-7:00	4		TUESDAY	er
26	19	12 Movement for PD, Flynn Arts, 10:00-11:30 Burlington PD Support Group, 1:00-2:30	5 Movement for PD, Flynn Arts, 10:00-11:30 NH HD Support Group, 6:00-7:30		WEDNESDAY	Movement Classes Support Groups Educational Opportunities Other Events
27 Addison Co. PD Support Group, 10:00-11:30	20 Movement for PD, Montpelier Senior Ctr, 10:00-11:30	13 Movement for PD, Montpelier Senior Ctr, 10:00-11:30	6 Movement for PD, Montpelier Senior Ctr, 10:00-11:30		THURSDAY	ities
28	21 Movement for PD, Saint Albans, 10:00-11:15 St. Johnsbury PD Support Group, 10:30- 12:00	14	7		FRIDAY	Universit
29/30/31	22	15 Mime Over Matter 10:30-12:00	8 Mime Over Matter 10:30-12:00 Brattleboro PD Support Group, 6:00	1 Mime Over Matter 10:30-12:00 Young Onset PD Support Group, 1:00-3:00	SATURDAY	MEDICAL CENTER

Burlington, VT 05401

MEDICAL CENTER

University of Vermont

- ЭНТ

Non-Profit Org. U.S. Postage PAID City, state Permit No. 2

BINTER CENTER NEWSLETTER | ISSUE #3 - FALL 2018

BINTER CENTER NEWSLETTER

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

NEWSLETTER EDITOR

Charlotte Gowen, Program Coordinator

NEUROLOGY

1 South Prospect Street Arnold, Level 2 Burlington, VT 05401

PHONE (802) 847-4589

FAX (802) 847-2461

WEBSITE UVMHealth.org/MedCenter/BinterCenter

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/MedCenter/BinterCenter or call (802) 656-2887.

