THE University of Vermont MEDICAL CENTER

Binter Center Newsletter Fall 2020

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TOP STORY: MENTAL HEALTH IN THE TIME OF COVID-19

A Message from the Binter Center

2020 has no doubt been a year of challenges. The impacts of the Covid-19 global health crisis that is affecting hundreds of thousands to millions of people around the world will be felt for years to come. As the country deals with the ongoing stress and uncertainty around Covid-19, it's important to remember that we all play a role in promoting connectedness, belonging, resiliency, and stopping the spread of the virus. Many within the Binter community are 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 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.

In this issue of the Binter Center newsletter, we've carefully crafted to provide 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 during this time to please 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 Cudhea, 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:

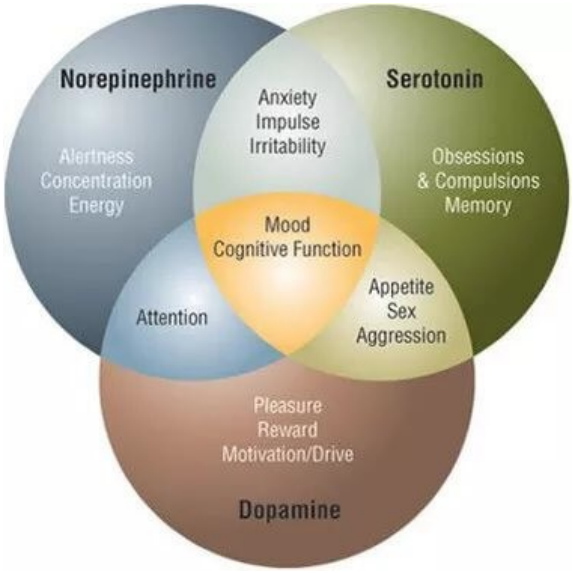
Dopamine (DA)- influences pleasure, reward/motivation and movements

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.



(image from:worldofcaffeine.com)

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 neurodegernerative 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.

Mood Changes Cont.

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
- NDRIs (norepinephrine dopamine re-uptake inhibitors)- bupropion
- TCAs (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.

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.

Mood Changes Cont.

"What happened to your spark?"

Apathy

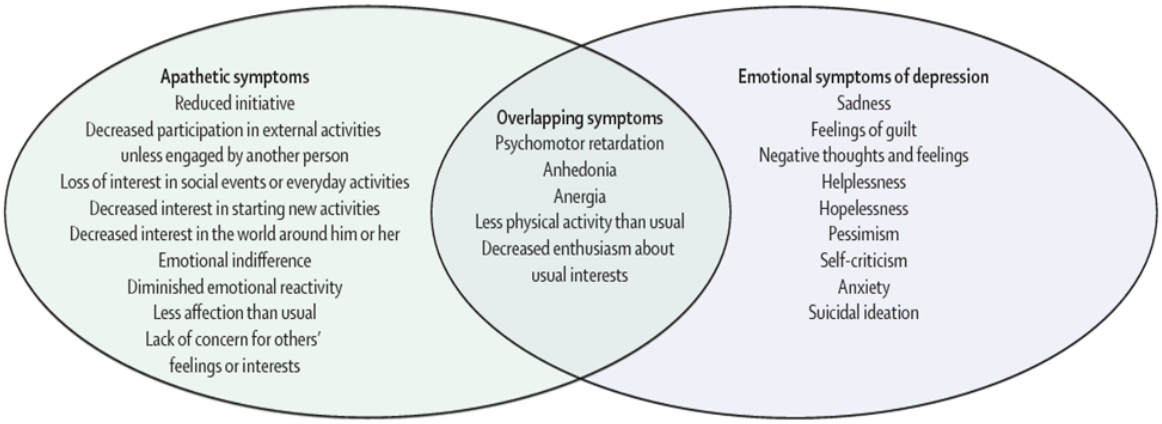
Apathy is a clinical syndrome under recognized in neurological conditions.

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.



(image from Lancet Neurology, May 2015. Pagonabarraga et al)

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

Mood Changes Cont.

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.

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

The Binter Center for Parkinson's Disease & Movement Disorders presents an "Ask the Dr." web series! Physician Dr. James Boyd, Director of the Binter Center will answers questions live about symptoms, treatments, and living with PD. This series will be held the first Tuesday of the month starting September 1, 2020, through December 1, 2020.

These sessions will be recorded, and 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

apda AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

Patient Aid Scholarship Program Application

APDA's mission: Every day, we provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.

The APDA Vermont Chapter offers a patient aid scholarship program designed to provide financial support to people with Parkinson Disease (PD) and their families. Approved applicants will be eligible to be granted up to $500 once per calendar year (January – December). Funds are limited and will be awarded on a first come basis. This Patient Aid Scholarship Program is intended for individuals with PD in need of financial assistance for programs, services and/or activities, such as:

- **Exercise/Wellness**: Supports costs associated with exercise/wellness programs and activities that focus on evidence-based treatment to improve and maintain the health for persons with PD. This is for exercise-related activities and classes such as, but not limited to: boxing, dancing, yoga, tai-chi, physical therapy, occupational therapy, etc.
- **Medication**: Defray expenses not covered by other programs or health insurance.
- **Respite Care/Adult Day Program**: Subsidizes the cost of respite care for the person with Parkinson's disease. Respite Care enables care providers to take time away from their responsibilities to rejuvenate.
- **Assistance at Home**: Covers expenses for home services, such as housework, light yardwork, snow shoveling, and other tasks that a person with PD or a care provider are not able to complete.
- **Transportation:** Covers costs associated with travel to and from doctor's appointments, support groups, and other events for those who are no longer driving or for whom driving is significantly limited due to the effects of Parkinson's disease.
- **Childcare Assistance:** Subsidizes the cost of childcare for people with Parkinson's.
- **Adaptive Equipment:** Offsets costs associated with the purchase and/or installation of equipment or modifications needed in the home to Aid in activities of daily living, such as, but not limited to: grab bars, hand rails, widening doorways, bathroom accessibility, etc.

For more information or to apply, please contact adpavermont@apdaparkinson.org or call 802– 847-3366

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.

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. Time: Every week on Mon, Thu, until Dec 10, 2020. **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. Next meeting will be November 14th. Please contact Sara Mcmahon at: movementforparkinsons@gmail.com.

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

Are you leading or in a support group that's not listed above? Please contact Binter Center social worker and support group coordinator, Lori McKenna at **lori.mckenna@uvmhealth.org** to register your group!

TEACH

A new therapeutic group for Caregivers of someone with Huntington's disease

Offered by the Frederick C. Binter Center for Parkinson's Disease and Movement Disorders at UVM Medical Center, an HDSA Center of Excellence; facilitator Lori P. McKenna, LiCSW

Topics include:

- Self-Care
- Resources and System Navigation
- Changes in Caregiving Relationship
- Planning for the Future

This group offers support, education, and skill building. It is open to any family member who is a caregiver for someone diagnosed with Huntington's disease. It may be especially helpful for someone who is experiencing increased caregiver responsibilities.

When: The TEACH Group will meet for 90 minutes, 10:00-11:30 AM on four consecutive Thursday mornings: Feb 4, Feb 11, Feb 18, and Feb 25, 2021.

Where: We remain committed to offering this group from the safety and comfort of your home utilizing the virtual platform ZOOM. Information will be provided during registration.

Cost: Participation likely covered by most insurances; co-payment may apply.

Interested? Call 802-847-1111 to speak to Lori or office manager, Megan Cross. *Group is limited to 7 participants.

October

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SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
				1	2	3
4	5 Dance for PD 10 am PushBack @ home seated 2 pm	6 "Ask the Dr."- Parkinson's Disease 6 pm PushBack @ home standing 2 pm	7 PushBack @ home seated 2 pm	8 Dance for PD 10 am PushBack @ home standing 2 pm	9	10
11	12 Dance for PD 10 am PushBack @ home seated 2 pm	13 PushBack @ home standing 2 pm	14 PushBack @ home seated 2 pm	15 Dance for PD 10 am PushBack @ home standing 2 pm	16	17
18	19 Dance for PD 10 am PushBack @ home seated 2 pm	20 PushBack @ home standing 2 pm	21 PushBack @ home seated 2 pm	22 Dance for PD 10 am PushBack @ home standing 2 pm	23	24
25	26 Dance for PD 10 am PushBack @ home seated 2 pm	27 PushBack @ home standing 2 pm	28 PushBack @ home seated 2 pm	29 Dance for PD 10 am PushBack @ home standing 2 pm	30	31

November

THE University of Vermont MEDICAL CENTER

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
1	2 Dance for PD 10 am PushBack @ home seated 2 pm	3 "Ask the Dr."- Parkinson's Disease 6 pm PushBack @ home standing 2 pm	4 PushBack @ home seated 2 pm	5 Dance for PD 10 am PushBack @ home standing 2 pm	6	7
8	9 Dance for PD 10 am PushBack @ home seated 2 pm	10 PushBack @ home standing 2 pm	11 PushBack @ home seated 2 pm	12 Dance for PD 10 am PushBack @ home standing 2 pm	13	14
15	16 Dance for PD 10 am PushBack @ home seated 2 pm	17 PushBack @ home standing 2 pm	18 PushBack @ home seated 2 pm	19 Dance for PD 10 am PushBack @ home standing 2 pm	20	21
22	23 Dance for PD 10 am PushBack @ home seated 2 pm	24 PushBack @ home standing 2 pm	25 PushBack @ home seated 2 pm	26 Dance for PD 10 am PushBack @ home standing 2 pm	27	28
29	30 Dance for PD 10 am PushBack @ home seated 2 pm					

December

THE University of Vermont MEDICAL CENTER

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
		1 "Ask the Dr."- Parkinson's Disease 6 pm PushBack @ home standing 2 pm	2 PushBack @ home seated 2 pm	3 Dance for PD 10 am PushBack @ home standing 2 pm	4	5
6	7 Dance for PD 10 am PushBack @ home seated 2 pm	8 PushBack @ home standing 2 pm	9 PushBack @ home seated 2 pm	10 Dance for PD 10 am PushBack @ home standing 2 pm	11	12
13	14 Dance for PD 10 am PushBack @ home seated 2 pm	15 PushBack @ home standing 2 pm	16 PushBack @ home seated 2 pm	17 Dance for PD 10 am PushBack @ home standing 2 pm	18	19
20	21 Dance for PD 10 am PushBack @ home seated 2 pm	22 PushBack @ home standing 2 pm	23 PushBack @ home seated 2 pm	24 Dance for PD 10 am PushBack @ home standing 2 pm	25	26
27	28 Dance for PD 10 am PushBack @ home seated 2 pm	29 PushBack @ home standing 2 pm	30 PushBack @ home seated 2 pm	31 Dance for PD 10 am PushBack @ home standing 2 pm		

BINTER CENTER NEWSLETTER

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Huntington's Disease Society of America Center of Excellence

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**.