

Binter Center Newsletter: The Caregiver Issue



A message from the Binter Center

“There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver.”, Former First Lady Roselyn Carter.

In this issue of the Binter Center newsletter we address the role of caregiving and provide resources for support. Currently in the United States there are over 60 million people providing care and support across lifespans. With 70% of family caregivers monitoring their loved ones' health conditions and care coordination, the need for support and resources for caregivers has never been more prevalent. In the Spring of 2025 we conducted a community needs assessment for people living with Parkinson's Disease and their caregivers. The caregiver survey responses indicated four areas of most concern: the alteration of the relationship dynamics between them and the person receiving care, concern for the future, the need for respite care and physical support, and the need for mental health and emotional support.

While the caregiver survey data collected was from the perspective of those supporting people living with Parkinson's Disease, providing care to someone, regardless of their diagnosis requires social, mental, physical, and emotional supports and resources. Our intention is to be as inclusive of all caregivers who may find this edition of our newsletter to be useful.

In Solidarity,

Dr. James T. Boyd, Binter Center Director

Brandolyn Bradley, Binter Center Program Coordinator

In This Issue

Welcome New Staff

(page 2)

The Journey of Caregiving

(page 2)

Community Events

(page 4)

In The News

(page 5)

National Resources

(page 6)

Local Resources

(page 8)

Program Offerings

(page 9)

Support Group Offerings

(page 14)

Research Offerings

(page 15)

Welcome New Staff!

We are excited to welcome a new staff member to our team.



Adeel A. Memon, MD, PhD

Dr. Adeel A. Memon joins the Department of Neurological Sciences at the Robert Larner, M.D. College of Medicine and the University of Vermont Medical Center as faculty in Movement Disorders Neurology. Dr. Memon is a board-certified neurologist with fellowship training in Movement Disorders from the University of Alabama at Birmingham (UAB). He holds a PhD in neuro-engineering, where his research focused on developing computational approaches to identify neurophysiological biomarkers for cognitive decline in Parkinson's disease. His Movement Disorders fellowship and PhD training were supported by an NINDS R25 Research Trainee Award from the NIH at UAB. Dr. Memon's clinical and research interests center on integrating artificial intelligence and advanced neuro-technologies into movement disorders care. He plans to build a multidisciplinary research program at UVM focused on neuro-AI applications, including early detection and predictive modeling for neurodegenerative diseases, brain-computer interfaces, non-invasive neuromodulation, and addressing disparities in neurological care.

The Journey of Caregiving

By Dara Stimson, LICSW



When a patient receives a life-changing diagnosis, another journey often begins alongside theirs—that of the caregiver. When people think of caregiving, we often think about the "doing": managing appointments, medications, transportation, or household responsibilities. While these practical tasks are certainly part of the role, caregiving is much more than that.

Caregiving affects nearly every part of life. It can be emotionally exhausting, physically demanding, financially stressful, and socially isolating. You may have heard about caregiver stress or burnout, and growing research continues to highlight the significant impact caregiving has on an individual's overall well-being. At the same time, there is increasing recognition that caregivers play an integral role in the health, quality of life, and outcomes of the person they are caring for. As our understanding of caregiving grows, an important question remains: How do we better support those who provide such essential care?

For many people, stepping into the role of caregiver is unexpected. It rarely comes with instructions or a clear picture of the road ahead. What we do know is that caregivers need support. When caregivers receive support and care for themselves, they are better equipped to care for their loved one—and both caregiver and care recipient benefit.

The Journey of Caregiving Cont.

One of the first steps is learning what resources are available. Look for caregiver support services in your community and organizations specific to your loved one's diagnosis, such as the [Lewy Body Dementia Association](#) or the [American Parkinson Disease Association](#). If you live in Vermont, the Senior Helpline (1-800-642-5119) can connect you with caregiver support services and resources such as respite grants. [Vermont 211](#) is another free and confidential resource for information and referrals. (<https://vermont211.org/>)

Just as important as finding practical resources is recognizing the emotional impact of caregiving. Caregivers often experience complex emotions including grief, guilt, shame, frustration, or resentment. These feelings are common and deserve to be acknowledged in a safe, informed, and supportive space. At the same time, caregiving can also bring moments of gratitude, love, pride, purpose, and hope. Holding both the challenges and the reward of caregiving is part of the experience.

Fortunately, caregiving is receiving more attention than ever before. Articles, books, documentaries, podcasts, and social media have helped bring greater awareness to the realities caregivers face. Peer support groups offer a unique opportunity to connect with others who truly understand the experience. As a facilitator of caregiver therapy groups, the most common feedback I hear is, "I don't feel so alone anymore," and "I feel hopeful again." Another connection I hear in our groups at the [UVMMC Dementia Family Caregiver Center](#) is that caregivers will often report thinking of each other in between groups and recall a laugh or a helpful tip. The strong peer support and connection is felt and received even between groups. That is the power of connecting with others who understand your journey.

Support groups are not the right fit for everyone, and that is okay. Individual therapy, caregiver-informed counseling, or simply reaching out to your loved one's healthcare team can also provide valuable support and guidance.

No matter where you are on your caregiving journey, there will be times when you feel stretched beyond your capacity. The following reminders may help you care for yourself while caring for someone else.

Learn to ask for help.

This is often one of the hardest adjustments for caregivers. Accepting help does not diminish your independence, it helps sustain your ability to continue caring for someone else. If someone offers to organize a meal train or run an errand, consider saying yes.

Know your boundaries.

Be honest with yourself about what you can and cannot do. Practice saying yes or no based on your own needs, not simply the expectations of others. Remember that boundaries can change as circumstances change. Identify your non-negotiables—whether it is your morning coffee, reading, exercise, time with family, or simply taking a shower without interruption—and protect that time.

Identify yourself as a caregiver.

Many people don't realize they have become caregivers, yet acknowledging this role can open doors to understanding and support. Let your employer, coworkers, family, and friends know about your caregiving responsibilities. A simple statement such as, "I'm caring for my parent right now, so let me check my schedule before I commit," helps others better understand your responsibilities. Learn about Family and Medical Leave Act (FMLA) benefits through your employer or explore Caregiver Supports through the Senior Helpline at 1-800-642-5119.

The Journey of Caregiving Cont.

Practice self-care.

Self-care is often misunderstood as something extravagant. While a massage or manicure can certainly be enjoyable, self-care is about intentionally making time for the activities that help you feel like yourself and restore your emotional and physical well-being.

Find connection.

Whether through a peer support group, therapy, or another trusted source of support, connecting with others can be one of the most sustaining parts of the caregiving journey. Even when solutions are not immediately available, feeling understood by someone who has walked a similar path can make all the difference. Check out a program like the Peer-to-Peer Mentoring Program at [UVMHC Dementia Family Caregiver Center](#) to see if it is a right fit for you.

Healthcare providers and medical teams also have an opportunity to support caregivers. Including caregivers as part of the care team, asking how they are doing, considering their capacity, and connecting them with helpful resources recognizes the vital role they play. Caregivers often provide valuable insight into a patient's daily life and can help fill important gaps in information that improve care.

This article is only one small piece of the much larger conversation surrounding caregiving, but I hope it serves as both a reminder and an acknowledgment of the important role caregivers hold. While caregiving can reshape nearly every aspect of life, it can also reveal extraordinary reserves of strength, adaptability, compassion, and resilience. Recognizing the emotional and psychological impact of caregiving is not simply about preventing burnout—it is about honoring the people who show up every day to provide care for their care recipient.

If you or anyone you know could benefit from support with caregiving for a person living with Dementia related symptoms contact us at [UVMHC Dementia Family Caregiver Center](#) or DFCC@UVMHealth.org.

Dara Stimson is a Licensed Clinical Social Worker At the UVMHC Dementia Family Caregiver Center. Dara is a trainer and co-facilitator of the VT CARERS group therapy program at UVMHC DFCC. Dara also has a private practice with a specialty in Older Adult Mental Health and offers support as a Per Diem Social Worker at UVMHHC.

Community Events

World Parkinson's Disease Day 2026!

On Saturday April 11, 2026 the Binter Center partnered with the Flynn Center for the Arts to celebrate the annual World Parkinson's Disease Day celebration This special awareness event showcased informative and interactive presentations of programs offered to our PD community. Presentations included PushBack at Parkinson's Disease™, PD Mime Therapy, Rocky Steady Boxing, and Movement for Parkinson's with Circle Sing. The presentations were followed by a flash mob on Church Street in Burlington.



World Parkinson's Disease Day program providers from left to right: M Sarah McMahon, Rob Mermin, Manuel Santiago, Lucas Kovacevich, Brandolyn Bradley, Rebecca Reynolds, Adina Panitch, Jody Albright, & Michael Bureau

Community Events Cont.

5th Annual Ashok Gupta Memorial Lecture in Parkinsonian Disorders

The Department of Neurological Sciences hosted the 5th Annual Ashok Gupta Memorial Lecture in Parkinsonian Disorders on Friday April 10, 2026 at the Davis Auditorium in the University of Vermont Medical Center and virtually through Zoom.

Dr. Lawrence Golbe, MD, was the visiting speaker for and the title of her talk was “*PSP et al: An Update on the Atypical Parkinsonian Disorders*”. The lecture was attended by nearly 100 people, including the Binter Center’s patients and their family members, and members of department of Neurological Sciences at the University of Vermont.

A recording of this year’s inaugural lecture can be viewed at the following weblink: tcrpd.org

This annual memorial lecture is co-hosted with collaboration of the Binter Center for Parkinson’s Disease & Movement Disorders at the University of Vermont Medical Center and the Ashok Gupta Foundation for Parkinsonian Disorders.



From left to right: Dr. Emily Houston, Dr. Lisa Deuel, Dr. Deepak Gupta, Dr Golbe, Dr. Vivikta Iyer, and Mr. Cole Zweber after the lecture on April 10th, 2026.

In The News

In May 2026 Vermont became the first state in the nation to ban the use of paraquat, a highly toxic herbicide linked to Parkinson’s Disease. The Binter Center was proud to work closely with the Michael J. Fox Foundation and Vermont Public Interest Research Group (VPIRG) to provide testimony to the Vermont House Agriculture Committee [Microsoft PowerPoint - Parkinson's disease and Paraquat.pptx](#), writing op-ed pieces in local newspapers [A chemical linked to Parkinson’s is still legal. That must change. - VTDigger](#), giving interviews on local news stations [Vermont debates banning popular herbicide](#), and advocating for Vermonters on the importance of the passage of this bill at press conferences.

We are proud of our state legislators for recognizing the importance of this and setting an example for the rest of our country. Thank you to everyone that helped make this happen for our communities!



Binter Center Program Coordinator, Brandolyn Bradley speaking at a press conference on April 15, 2026.

National Resources for Caregivers



AARP's Caregiving Resource Center provides tools, expert advice, and support for family caregivers. It includes guides, checklists, and access to a community of caregivers. Please visit: www.aarp.org/caregiving/



The American Parkinson Disease Association (APDA) is a nationwide grassroots network dedicated to fighting Parkinson's disease (PD) and works tirelessly to help the approximately one million with PD in the United States live life to the fullest in the face of this chronic, neurolog-

ical disorder. APDA provides an array of programming for care partners, including topics specifically for spouses and partners navigating the impacts of PD on intimacy and sexuality.

Please visit: www.apdaparkinson.org/resources-support/for-care-partners/



ARCH National Respite Network and Resource Center connects caregivers with respite services and offers training, advocacy, and research tools. Their national directory helps families locate local respite care options.

Please visit: <https://archrespite.org>



This organization offers free education, peer support, and resources for family caregivers across the U.S. Their site includes videos, tip sheets, and a caregiver help desk. Please visit www.caregiveraction.org



CARINGBRIDGE™

CaringBridge is a nonprofit platform that allows individuals facing health challenges to create private, ad-free pages for sharing updates, coordinating support, and connecting with loved ones. It helps caregivers and patients communicate efficiently, request help, and feel less alone during medical journeys. Please visit caringbridge.org



**Family
Caregiver
Alliance®**

Family Caregiver Alliance provides services, education, and advocacy for caregivers of adults with chronic or disabling health conditions. Their site includes fact sheets, webinars, and a caregiver support program. Please visit www.caregiver.org



Lotsa Helping Hands

Lotsa Helping Hands is a free service that helps caregivers organize support from family and friends. Users can create care communities to coordinate meals, rides, and other tasks.

Please visit: <https://lotsahelpinghands.com>

National Resources for Caregivers Cont.



**NATIONAL ALLIANCE
FOR CAREGIVING**

This nonprofit conducts research and develops policy to support family caregivers. Their site includes reports, advocacy tools, and global caregiving initiatives. Please visit: www.caregiving.org



Administration for Community Living

National Family Caregiver Support Program (Administration for Community Living is a federal program offers grants to states to support family caregivers through services like counseling, training, and respite care.

Please visit: <https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>



Parkinson's Foundation is a non-profit organization dedicated to making life better for people living with PD and their families by improving care and advancing research towards a cure. Their care partner resources are broken into three sections: Early in the Journey, Care for the Care Partner, and Care From Afar. Please

visit: www.parkinson.org/resources-support/carepartners.



THE CARTER CENTER

The Rosalynn Carter Mental Health and Caregiver Program through The Carter Center's Mental Health Program, founded by former First Lady Rosalynn Carter, works to improve mental health care and support caregivers by advancing public policy, reducing stigma, and promoting equity. The program includes global initiatives, journalism fellowships, and caregiver support services, all aimed at strengthening mental health systems and raising awareness about behavioral health challenges.

Please visit: www.cartercenter.org/programs/mental-health-and-caregivers/



Well Spouse Association is a nonprofit that offers peer support and advocacy for spouses caring for a chronically ill or disabled partner. Members can access support groups, newsletters, and events.

Please visit: <https://wellspouse.org>

Local Resources for Caregivers



Age Well Vermont's mission is to empower and support individuals as they are by providing community connection and access to services. Age Well provides services to Northwestern Vermont. Age Well offers program to support caregivers. Age Well serves Addison, Chittenden, Franklin, and Grand Isle Counties.

Please visit: www.agewellvt.org/caregivers/



Central Vermont Council on Aging's mission is to connect Vermonters to benefits and services such as personal care, household help, housing, transportation, and more! CVCOA serves Washington, Lamoille, and Orange Counties as well as the towns of Bethel, Hancock, Granville, Rochester, Royalton, Sharon, and Stockbridge.

Please visit: www.cvcoa.org/for-caregivers



The Northeast Kingdom Council on Aging provides services from nutrition and wellness to caregiver support and case management. NEKCOA serves Caledonia, Essex, and Orleans Counties.

Please visit: www.nekcouncil.org/copy-of-caregiver-support



Senior Solutions offers guidance to older Vermonters, provide caregivers build robust support systems for their loved ones, and coordinate transportation. Senior Solutions serves Windham and Windsor Counties (except for towns of Bethel, Rochester, Royalton, Sharon, and Stockbridge; includes towns of Searsburg, Readsboro, Thetford, and Winhall).

Please visit: www.seniorsolutionsvt.org/services/caregiver-support



Southwestern Vermont Council on Aging's mission is to empower Vermonters to age with dignity by providing client-centered, collaborative, compassionate, and creative supports. SVCOA provides resources for Rutland and Bennington Counties. Please visit: www.svcoa.org/caregiver-support-services/

Program Offerings

Movement for Parkinson's

Movement for Parkinson's is a Dance for PD ® certified program that engages people with Parkinson's in a research-backed dance class. The program's mission is for people with PD to enjoy and benefit from specialized live and virtual dance instruction and to provide transformative, life-enhancing opportunities that celebrate creativity, community, movement, and music.

Classes are held in-person and via Zoom by Dance for PD-certified teaching artist Sara McMahon. For more information, please contact Sara at movement.for.parkinsons@gmail.com

PushBack at Parkinson's Disease™

PushBack at Parkinson's Disease® is a medically advised, community-supported group exercise program offered by the Frederick C. Binter Center for Parkinson's Disease and Movement Disorders at the University of Vermont Medical Center. The program is designed by physical therapists to help improve the strength, flexibility, and agility of those living with PD. The program brings together local exercise facilities, professionals, and volunteers who are compassionate, enthusiastic, and knowledgeable about helping people with PD through exercise strategies.

Classes are held in person and via Zoom by local coaches. For more information, please contact PushBack Program Manager Brandolyn Bradley at Brandolyn.bradley@uvmhealth.org

Rock Steady Boxing

Rock Steady Boxing® is a non-contact, boxing-based fitness program that aims to improve the quality of life of people with Parkinson's Disease. Classes are currently held in St. Albans, Williston, and Lyndonville.

For more information, please contact:

St. Albans: Collins Perley Sports & Fitness Center 802-527-1202

Williston: Sydney Swindell sydney.swindell@gmail.com

Lyndonville: Joe Allard 802-535-4520

Tai Chi for PD

Seated Tai Chi incorporates many principles of Tai Chi: continuous and flowing movements; awareness of body alignment and position in space. Classes are held in person and are taught by Adina Panitch, a certified Tai Chi instructor. For more information, please contact Adina apanitch@aol.com

Mindfulness for PD

Mindfulness is a tool for emotional resiliency and coping with stress, especially in the face of chronic, progressive illness. Through practicing mindfulness of body, breath, and environment, we can practice being present and aware with an array of human experiences – from the simple, to the complex and challenging. Mindfulness offers us a choice for how we approach the vicissitudes of our lives.

For more information, please contact Lucas Kovacevich at lucas.kovacevich@uvmhealth.org

Program Offerings Cont.



What Are SPEAK OUT! Classes?

At the conclusion of individual SPEAK OUT! therapy, participants transition to weekly SPEAK OUT! Classes. These sessions provide ongoing speech practice, education, and support to help maintain and strengthen communication skills.

Who Can Attend?

Anyone who has completed individual SPEAK OUT! therapy is welcome to join.

Where

Dunbar Conference Room
Fanny Allen Campus
790 College Parkway
Colchester, VT 05446

When

Mondays 3:00-4:00 p.m.

Led By

A Certified SPEAK OUT! Provider

Cost

Free!

Interested in Joining?

Contact Speech-Language Pathology
802-847-3970

rehabtherapies-slpaud-supportstaff@UVMHealth.org

Program Offerings Cont.



University of
Vermont Health

The VT CARERS Program for Dementia Family Caregivers: Fall 2026

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

FALL Schedule 2026

What is the CARERS Program?

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

What is the TEACH Program?

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

Logistical Information:

1. **TEACH:** Monday Sept 28 2026-October 19, 2026. Time: 1:00-2:30. Facilitator, Lori P. McKenna, LICSW
2. **CARERS Care Partners /Spouses:** Thursday September 17, 2026-Thursday November 5th, 2026 Time: 1:00-3:30. Facilitator Dara Stimson, LICSW
3. **CARERS Adult Children:** Wednesday September 16, 2026-November 4, 2026. Time: 4:00-6:00. Facilitators: Joan Marsh-Reed, MA.

For other groups anticipated but not yet scheduled please contact the Dementia Family Caregiver Center for updates at 802-847-4589.

Program Offerings Cont.

The VT CARERS Program for Dementia Family Caregivers: Fall 2026

Commitment:

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

Skills Learned:

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

Fees:

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

Additional Information and How to Register:

If you or someone you know is interested in finding out more about the VT CARERS program, or if you would like to be considered for the group, please contact Lori P. McKenna, LICSW or Joan Marsh-Reed, MA at 802-847-4589 or by email at DFCC@UVMHealth.org. A pre-assessment interview is required prior to joining the group. We recommend that those with interest sign up soon; space may be limited.

Have You Cared for a Family Member with Dementia?

Seeking volunteer mentors to help mentees new to dementia caregiving, in our upcoming Peer to Peer Mentoring Program. Share your skills, give back, ease isolation, offer listening, guidance and compassion. Contact UVM Health Dementia Family Caregiver Center at DFCC@uvmhealth.org to learn more.

Are You a Caregiver Currently Caring for a Family Member with Dementia?

The Peer to Peer Mentoring Program will match family caregivers (mentees) with former caregivers with lived experience (mentors) in this 6 month volunteer program. This experience will provide support and guidance to you, with someone who understands the challenges caregivers face, someone who has been there. Through this, you will feel supported and encouraged, learn about valuable resources, and benefit from the experiences of a peer. Contact UVM Health Dementia Family Caregiver Center at DFCC@uvmhealth.org to learn more.

Support Group Offerings

Parkinson's Disease

Group	Meeting Schedule	Meeting Location	Contact Information
Brattleboro, VT	Monthly 2 nd Saturday 10 – 11:30 am	Brattleboro Memorial Hospital Tyler Room 17 Belmont Ave Brattleboro, VT Virtual Group Currently	Diane Nichols diane.nichols53@gmail.com (603) 756-3089
Burlington, VT “People with Parkinson’s (PWP) Support Group” (Only for people with PD.)	Monthly 3 rd Wednesday 12 pm – 1:30 pm	Fletcher Free Library 235 College St Burlington, VT Virtual Group Currently	Jennifer Pader LMSW westsidetherapy350@gmail.com
Danville, VT	Monthly 3 rd Friday 10:30 am-noon	Danville Community Building Danville, VT	Dan & Mary Swainbank swainbank@danvillevt.net (802) 535-0031 (Dan’s Cell) (802) 535-0412 (Mary’s cell)
Rutland “The Fighters”	Monthly 1 st Monday 4 pm-5 pm	Godnick Center 1 Deer Street Rutland, VT	Lee Accavallo (802) 353-8838 lee@royalvt.com
St. Albans	Monthly Tuesdays 10 am– 11:30 am	Pillsbury Homestead 64 Harbor View Drive Saint Albans, VT	Jarrig Visser (802)-308-0679
St. Johnsbury, VT CAREGIVERS	Monthly 1 st Wednesday 2 pm	Universalist Unitarian Meeting House 47 Cherry Street St. Johnsbury, VT (across from catamount Arts)	Linda Cochrane lindajchrane@gmail.com (845)-849-6562
“Vermont PD Support Group” (For PWP & their care-givers)	Monthly 2 nd Saturday 1 pm – 2:30 pm	Virtual Group Offering	Chris Hansen itschrishansen@gmail.com

For other support group offerings, or if you are leading a support group not listed, please contact Binter Center Social Worker, Lucas Kovacevich at lucas.kovacevich@uvmhealth.org or 802-847-9788.

Research Offerings

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

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

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

You may be eligible if you:

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



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

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

Research Offerings Cont.

Help us explore a new treatment for **Huntington's disease.**

As someone living with Huntington's disease, you know the impact it can have on daily life – both for you and the people closest to you. While current treatments can help manage symptoms, they can't slow the progression of the disease itself. That's why we're conducting INVEST-HD – a clinical study to see if an oral investigational medicine could help slow the progression of Huntington's disease. Research studies like this help us learn more about the condition and may help others in the future.

Who can take part?

We're looking for about

770  people

to join the INVEST-HD study, who, among other criteria:

- Are aged between 21 and 70
- Have a gene-positive test result confirming Huntington's disease, with a CAG repeat length of 40 or above
- Are in the early stages of Huntington's disease (which means having mild or unnoticeable symptoms)



[Study team contact details]

Principal Investigator: Dr James Boyd
james.boyd@uvmhealth.org

Study Coordinator: Nasim Nehzat
nasim.nehzat@uvmhealth.org

Research Offerings Cont.



PD-CFI STUDY

(Implementation of the PD-CFI Classification Scheme for Studying Cognitive dysfunction in Parkinson's Disease.)

We are seeking participants for a research study evaluating a new classification scheme for studying cognitive functions impairment in Parkinson's disease (abbreviated as PD-CFI). This computer-based approach aims to diagnose cognitive impairment in Parkinson's disease and predict its progression, compared to traditional methods.

The study involves two visits, one year apart, and is observational with no changes in treatment. During the visits, we will ask about your health, medications, and environment, and conduct physical and neurological exams with questionnaires.

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

- You have been diagnosed with Parkinson's disease and are currently experiencing cognitive symptoms (with or without diagnosis of cognitive impairment).
- You are 18 years or older in age.

For more information about the study, please contact the lead investigator, Dr. Deepak Gupta, through the study coordinator at (802) 341-8119.

Thank you to everyone who is currently participating in one of our studies, or has in the past. We couldn't move our understanding of movement disorders and therapies forward without you!

Research Offerings Cont.

A natural history study of treated Parkinson's disease patients experiencing motor complications

You may be eligible to participate in this research study if you:

- are 45 – 75 years old,
- were diagnosed with Parkinson's disease 4-12 years ago,
- are taking a levodopa-based treatment to control motor symptoms (with a daily dose of 300mg or more or a dosing frequency of 3 or more times per day), and
- have at least 1 hour of off-time each day.

What to expect:

The study will collect data on:

- Sociodemographics,
- Medical history and vital signs,
- Medications and treatments,
- Movement and non-movement symptoms,
- Burden of care, etc.

The data will come from questionnaires and rating scales collected by the doctor during study visits, diaries and logs completed by the patient and their care partner, medical records, and other optional sources (e.g. health insurance records, blood samples, skin biopsies).

Main objective:

To better understand how Parkinson's disease (PD) progresses over time in patients who experience movement symptoms while taking standard oral PD medications.

This is an observational research study, which means no investigational product will be administered.

Each participant will have a study visit every 6 months and may be followed for up to 5 years.



The study doctor will explain all the requirements to you. Being in a study is voluntary and you can leave the study at any time.

Reasonable reimbursement costs for you and your care partner may be provided throughout the study.



Ask your doctor, learn more at clinicaltrials.bayer.com/study/23021 or call us at 802-847-1534 for more information.
Nasim.Nehzat@uvmhealth.org

Research Offerings Cont.

Scan here for more information

Summary of the PARAISO study BN44715

This Phase III study aims to see if a study drug called prasinezumab can help people who have early-stage Parkinson's disease. Parkinson's disease is a condition of the brain that affects a person's ability to control their movement. Researchers want to see if this study drug can make you feel better and move more easily, or if it slows down the disease progression. This study will also check the safety of the study drug.



Screening 1.5 months

Doctors will check if you're a good fit for the study and that the study is a good fit for you

Treatment At least 2 years

- You'll get either prasinezumab or a placebo, which looks just like the study drug but contains no active medicine
- Visits to clinic will be monthly and take about 4–6 hours
- You will continue to get your usual levodopa treatment during the study

Follow-up Up to 2.5 months

- Doctors will continue to monitor your health after treatment stops.
- There's also a chance to take part in an additional 2-year extension where everyone will receive the active drug prasinezumab (no placebo).



No Time to Waste

exPDite-2 is a phase 3 study evaluating the potential efficacy and safety of a 1-time investigational cell therapy called bemdaneprocel on movement, balance, motor symptoms, and quality of life in adults with Parkinson's disease.



When implanted into your brain in a 1-time surgery, bemdaneprocel may replace dopaminergic neurons lost from Parkinson's disease, with the aim of integrating into the brain to produce dopamine.

Ask your doctor, learn more at www.exPDiteStudy.com or call us at +1-877-380-3967



What to expect

Participating in exPDite-2 includes a screening phase, a 1-time surgery, ongoing monitoring, and long-term follow-up with the study team. You may receive the study medicine or a simulated surgery.

We understand that participating in a study is a big decision. Talk with your family, doctors, or others who suffer from Parkinson's disease.

Contact

Komal Mehta — Research Coordinator
(802) 847-1597

Komal.Mehta@uvmhealth.org

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!

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Binter Center Newsletter

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