

Binter Center Newsletter

Fall 2024

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THE RESOURCE ISSUE



A Message from the Binter Center

Providing a patient-centered approach to healthcare is at the heart of our mission. We believe that working with our community helps us to provide access to the resources our patients need to help them manage their health. Working at the community level provides the opportunity to reduce the gaps in services often caused by differences in income, location, and access to transportation. We take great pride in our efforts to engage local community leaders, community-based organizations, and national partners to provide you with access to diverse resources. We are grateful to our many partners and remain steadfast in our commitment to providing a multidisciplinary team-based approach to addressing the needs of our patients and their families.

In Solidarity,

Dr. James T. Boyd, Binter Center Director

Brandolyn Bradley, Binter Center Program Coordinator

Welcome New Staff

We are excited to welcome new staff members to the Frederick C. Binter Center for Parkinson's Disease & Movement Disorders at the University of Vermont Medical Center. Read on to learn about the additions to our team and the essential roles they play in helping us provide quality healthcare.



Mary Collins, Research Coordinator II

Mary Collins joined the Binter Center team in February 2024 as a Research Coordinator. Mary is born and raised in Williston, VT. She earned a Bachelor of Science in Neuroscience and Business Administration from the University of Vermont in addition to completing the Pre-Med Post-Baccalaureate Program. Mary joins us from the Davids Lab at the Dana-Farber Cancer Institute where she has spent the last five years as a senior research technician and operations coordinator. Mary's passion for Neuroscience is inspired from volunteering in the pediatrics unit at the University of Vermont Medical Center, where she met a young boy with neuroblastoma. She has remained active in multiple organizations that are working on legislative change for those with disabilities. When she is not working or volunteering, Mary enjoys an active lifestyle and spending time with her family. Mary's favorite part of her job includes building comradery with the Binter team and having increased one-on-one time with patients.



Lucas Kovacevich, MSW, Social Worker,

After spending a year with our team as a social work intern, Lucas Kovacevich joined our Binter Center team in the Fall of 2023. Lucas grew up outside of Syracuse, New York with his two siblings. He earned his undergraduate degree from SUNY New Paltz, a master's degree in English from the School for International Training and a masters in social work (MSW) from the University of Vermont. Lucas has had quite the adventurous journey in his career, having served as a high school teacher in New York City teaching English to English second language students. He was a farmer in Illinois, lived in a Buddhist community in Barnet, Vermont, and worked as a farmer in Nova Scotia. Lucas has not had a typical pathway to social work but found a deep desire to provide direct service to those in need.

New Staff Cont.

Lucas enjoys sitting with people as a safe person to discuss life's challenges and joys. Outside of work Lucas enjoys being an uncle, gardening, practicing meditation, and having adventures with his pup Merlin.



Rebecca Pratt, MD Movement Disorders Fellow

Rebecca Pratt joined the Binter Center team July 2024 as the Movement Disorders Fellow for the 2024-2025 academic cycle. She grew up in Florida and Alabama. She earned her undergraduate degree from North Carolina State University, went to medical school at Trinity School of Medicine, and completed her residency from the University of Arkansas for Medical Sciences. Becca was inspired to become a doctor when she was eight years old listening to a physician talk to her grandparents about neurosurgery. Becca loves the outdoors, hiking and kayaking. She also enjoys trivia nights and karaoke. She also enjoys having adventures with her husky, Toby. Becca has been enjoying her time in Vermont, exploring Burlington and Winooski's food scene, and getting to know her neighbors.



Sarah Tandan, NP, Movement Disorders Nurse Practitioner

Sarah Tandan is a native Vermonter and has been a nurse practitioner for over ten years. After completing her master's in nursing, she initially worked in the Boston area at a community health center. She moved back to Vermont just in time to welcome her daughter and has enjoyed settling back into the Vermont lifestyle. She was inspired to enter the healthcare field by her parents (mother is a retired nurse and father is a neurologist). She joined the Binter Center in the Fall of 2023 after wanting to pursue specialty training in neurology. She values a holistic approach to healthcare and deeply enjoys developing meaningful relationships with her patients and colleagues. In her free time, Sarah enjoys spending time with her husband, two young kiddos, and large Anatolian Shepherd. She can often be found gardening, hiking, doing yoga, or reading. Sarah appreciates a life surrounded by music and can often be heard singing.

Community Spotlight: Sara McMahon



Sara McMahon is a certified Dance for PD[®] (DfPD) instructor and a long-time supporter of the Binter Center. For those that are unfamiliar, Dance for PD is an internationally acclaimed program that offers research-backed dance classes for people with Parkinson's disease. Classes seek to engage people with Parkinson's around the world to enjoy and benefit from specialized live and virtual dance instruction. Sara has been involved in the research, teaching, performing of movement as a form of artistic and personal development for over 40 years. She believes that dancing has been her way of seeing and being in the world and that teaching has been a way for her to connect to others in a way that is magical and transcendent. Sara's background as a dance educator included not only forms of Ballet, Modern and Improvisation, but also extensive study of the science of movement.

Along with being a movement artist/educator Sara worked for over 20 years as a Licensed Clinical Mental Health Counselor in Vermont and Alaska. When her husband Gary was diagnosed with Parkinson's – PSP in 2012 she began to shift her focus to teaching movement classes to the Parkinson's community in Vermont. After attending an Intro to Dance for PD workshop in 2013, Sara knew she found the program that would provide the education and support needed to develop a program in Vermont. She immediately thought of designing a class specifically for people with Parkinson's and in 2013/14 the Movement for Parkinson's (MfPD) program at the Flynn Center for the Performing Arts was born. Sara and her husband Gary live in Jonesville, Vermont where they enjoy gardening and time with their daughter and grandchildren.

The Binter Center is fortunate to partner with Sara and the Flynn Center for the Performing Arts in Burlington, Vermont to provide this vital program to those living with Parkinson's across the state. Currently there are in-person classes being held at the South Burlington Senior Center and a virtual offering. Additional in-person classes will be offered in Montpelier and Barre in the Fall of 2024. Classes are 60 minutes and feature live and recorded music. Those with Parkinson's of all abilities and degrees of mobility are encouraged to participate along with their partners, carers, spouses, and friends. No dance experience is necessary to join this vibrant community. For information on Dance/ Movement for PD classes email saramcm28@gmail.com or visit flynn.org.

Program Spotlight: PushBack at Parkinson's Disease®



PushBack at Parkinson's Disease ® (PBPD) is a medically advised, community supported group exercise program designed to help improve the strength, flexibility, and agility of people with Parkinson's Disease (PD). PBPD brings together local exercise facilities, professionals, and volunteers who are compassionate, enthusiastic, and knowledgeable about helping people with this disease

through exercise strategies.

PBPD began in 2015, growing from IDEAL (Individualized Exercise Designed for Active Lifestyles). IDEAL began as an exercise program for people with Multiple Sclerosis that was adapted for PD. The development of PBPD came from two enthusiastic Physical Therapists who held a vision of creating a program where participants could feel their best while managing their symptoms. With the support of Vermont Adaptive Ski & Sports (VASS), the program began in Winooski, VT with a handful of volunteers. By mid-2017, PBPD graciously received a large anonymous donation to support the program and drive expansion efforts.

Over the years, PBPD has expanded throughout Chittenden County, Middlebury, Barre, and St. Albans. In 2020, due to the Covid-19 global pandemic, the PBPD leadership team quickly adapted the program to provide a virtual option. It was this ingenuity that maintained opportunity for our community members to continue participating in this much beloved program. By mid-2022 PBPD was officially trademarked, protecting the integrity of the program while preventing infringement and providing an additional layer of trust to all involved with the program.

While PushBack at Parkinson's Disease ® has experienced monumental challenges over the years, the true testament of the program's resiliency lies with the "players," coaches, and volunteer partners. Without their dedication, the program could not have evolved into the a cornerstone of our community it is today. The positive energy and comradery from all that engage in this program propels it forward. The Binter Center is proud to have secured the resources necessary for our flagship program to continue in perpetuity. To learn more about how you can support PBPD, please contact PushBack Program Manager, Brandolyn Bradley at Brandolyn.bradley@uvmhealth.org

Community Events

World Parkinson’s Disease Day 2024!



On Thursday April 11, 2024 the Binter Center partnered with the Flynn Center for the Arts to celebrate World Parkinson’s Disease Day! This special celebration 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, Mindfulness for People with PD, and Movement for Parkinson’s with Circle Sing. The presentations were followed by a flash mob on Church Street in Burlington.

3rd Annual Ashok Gupta Memorial Lecture in Parkinsonian Disorders



(Pictured above: Dr. James Boyd, Dr. Amie Hiller, and Dr. Deepak Gupta)

On Friday April 29, 2024 the Ashok Gupta Foundation for Parkinsonian Disorders in partnership with the Binter Center hosted the 3rd Annual Ashok Gupta Memorial Lecture in Parkinsonian Disorders with guest speaker Dr. Amie Hiller.

Dr. Hiller is the Director of the Pacific Northwest VA Parkinson’s Disease Research, Education, and Clinical Center (PADRECC), a practicing movement disorders neurologist at the Portland VA Medical Center (PVAMC), and an Associate Professor at Oregon Health Sciences University

Community Events Cont.

(OHSU). Dr. Hiller is also the Director of the Movement Disorders joint fellowship program at PVAMC & OHSU. Dr. Hiller gave a inspiring lecture on “Redefining Parkinson’s Disease: A Review of New Staging & Classification Systems”. A recording of the event can be found at bit.ly/2024agml.

Binter Center-Parkinson’s Foundation Spring Event



(Pictured above: Melody McLaughlin of the Parkinson’s Foundation, Lucas Kovacevich, Brandolyn Bradley, Dr. Suzanne Kennedy, and Dr. James Boyd of the Binter Center.)

On Friday May 17, 2024 the Binter Center and the Parkinson’s Foundation partnered to host “Social & Emotional Well-being in PD”. This educational half-day event engaged attendees on topics including “The Impact of Non-Motor Symptoms of PD on Mental Health”, mindfulness exercises, and an update on PD research. A recording of the event can be found at <https://youtu.be/9st49whXyS0>

In The News



Pictured above: President Biden signs the National Plan to End Parkinson’s Act into law. Photo courtesy of the Biden administration.

On July 2, 2024 President Biden signed the National Parkinson’s Project into law. This is the first-ever federal legislation dedicated to ending Parkinson’s disease (PD).

This monumental bill can make an impact by:

- Dramatically increasing federal research funding.
- Developing more effective pathways for treatments and cures.
- Improving early diagnosis.
- Sparking new and improved models for patient care.
- Addressing health disparities in diagnosis, treatment and clinical trial participation.

On behalf of the over 12,000 people living with Parkinson’s Disease in Vermont, the Frederick C. Binter Center for Parkinson’s Disease and Movement Disorders

at the University of Vermont Medical Center would like to thank our Congressional delegation for their work on passing this historic legislation. The passage of this bill will provide organizations like ours the opportunity to expand our work in the state of Vermont. We applaud Senators Sander and Welch and Congresswoman Balint for their efforts and are grateful to have such dedicated members of Congress to advocate for the legislation so many in our state need.

Local Resources



The University of Vermont



- Do you have Parkinson's and experience challenges with your voice?
- Do you want to retain your speech and communication and minimize future swallowing complications?
- Are you feeling the desire to communicate with others, be a part of a group, and create new connections?
- Have you completed the SPEAK OUT!® program?

The LOUD Crowd® program might be a good fit for you!

What:

The University of Vermont Eleanor M. Luse Center is pleased to now offer the LOUD Crowd® program. This program is developed by The Parkinson's Voice Project, a 501(c)(3) nonprofit organization dedicated to improving speech and communication in individuals with Parkinson's. The LOUD Crowd® is a weekly maintenance program which follows the completion of SPEAK OUT!®, a one-on-one speech therapy program. You must have completed the SPEAK OUT!® program before starting the LOUD Crowd®. Sessions provide vocal practice, accountability, support, and encouragement. The group component of this program promotes interaction and genuine communication!

Where/When:

Sessions occur every Wednesday via Zoom.
Sessions run from 10 – 11am

Sign-up Info:

Call the UVM Eleanor M. Luse Center at:
(802) 656-3861

***For more information about Speak Out, please contact your treatment team**



Local Resources Cont.



Age Well is a nonprofit organization that serves Vermonters 60 years of age and older in Addison, Chittenden, Franklin, and Grand Isle Counties and is the largest Meals on Wheels provider in Vermont.

Our mission is to provide the support and guidance that inspires our community to embrace aging with confidence.



COMMUNITY AGING IN PLACE ADVANCING BETTER LIVING FOR ELDERS

The CAPABLE program helps older adults function safely in their homes. Teams comprised of an occupational therapist, a registered nurse, and a handyperson to help older adults identify their own self-care goals which can decrease hospitalization and healthcare costs. To address these goals, CAPABLE evaluates both the home environment as well as the strengths and resources of the older adults' themselves.

CAPABLE services involve up to:

- 6 home visits from an Occupational Therapist
- 4 home visits from a registered nurse
- Minor home repair, modifications, & assistive devices

CAPABLE program is offered to participants at no cost.

Eligibility

- 60 years of age or older
- Live in Addison, Chittenden, Franklin, or Grand Isle counties
- Have some difficulty with any ADL (such as bathing, dressing, grooming, eating, walking across a small room)
- Cognitively intact
- Not receiving active cancer treatment or pending surgery (may be able to waitlist until events are completed)
- Not terminally ill
- Income eligible - call for more information

CAPABLE IMPROVES OUTCOMES FOR PATIENTS

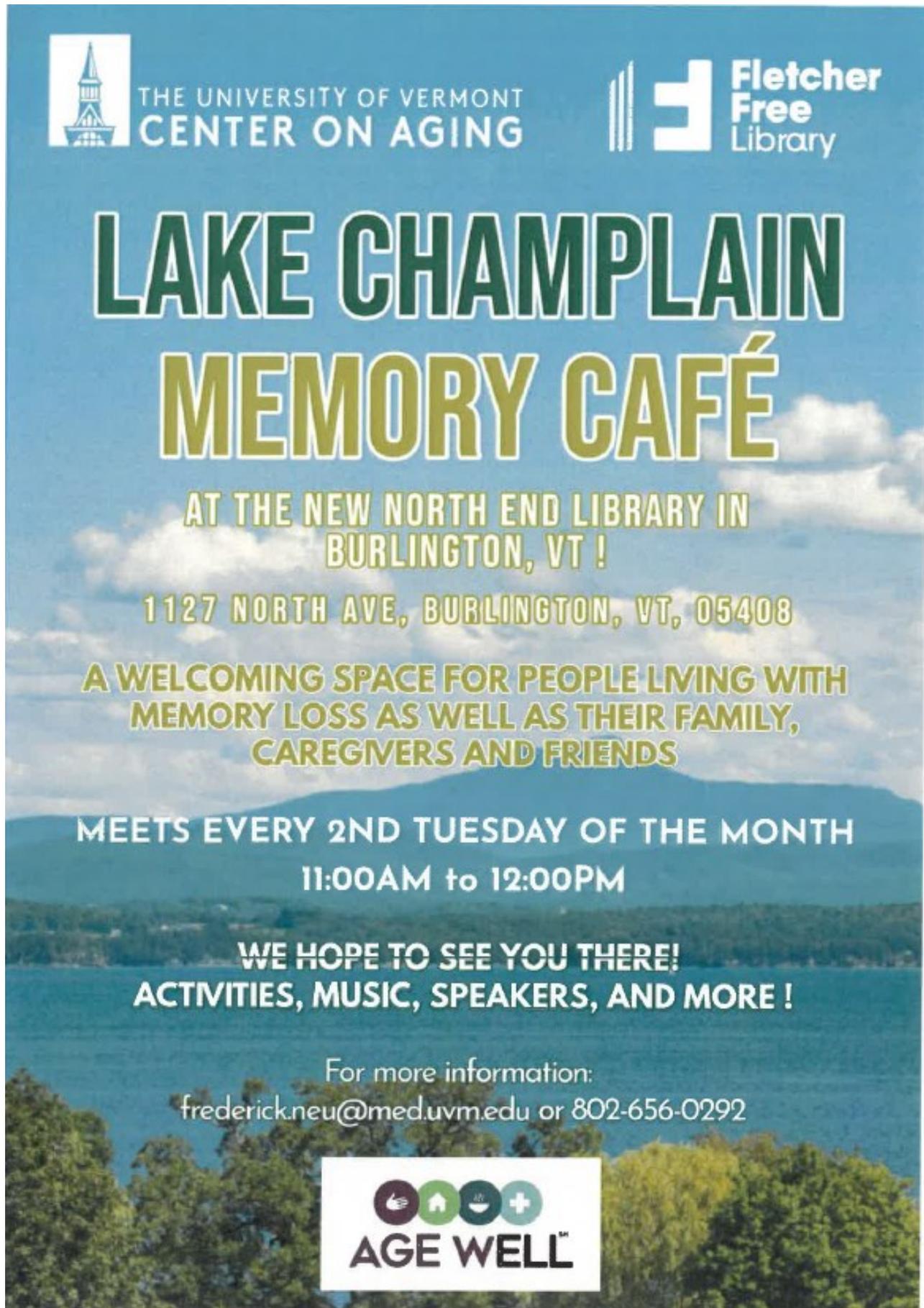
In a population of low-income older adults who participated in CAPABLE, 75% of participants improved their self-care over 5 months. ¹

- The average CAPABLE participant was able to cut their disability in half
- Participants experienced a decrease in symptoms of depression
- Preliminary results suggest that CAPABLE cuts inpatient costs by 34% compared to a comparison group

¹Data from September 2016 paper Health Affairs and January 2015 paper in the Journal of the American Geriatrics Society.

**QUESTIONS & REFERRALS:
1-800-642-5119**

Local Resources Cont.



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Local Resources Cont.

PRESS Program **Parkinson Roadmap for Education and Support Services**

The PRESS Program is an 8-week group that provides an opportunity for people with Parkinson's disease and their care partners to meet with others facing a similar experience. The group is for those who have been diagnosed within the last five years and focuses on the sharing of management and coping strategies for day-to-day challenges related to living with PD. It is a place to share feelings in a safe, caring environment as well as a place to gather information about resources.

Each session is 90 minutes and is built around a specific topic (i.e. exercise, medication management, understanding symptoms). The first two sessions are open to new members but the group is closed after the second session; a waiting list is created for the next time the group is offered. The group has room for a maximum of 15 participants that commit to attend for the full eight weeks. The fall group will likely be held virtually through Zoom. For more information, please reach out to Joan Marsh-Reed at Joan.Marsh-Reed@uvmhealth.org.



Central Vermont Council on Aging (CVCOA) serves adults 60 and older living in Central Vermont, their caregivers, partners and families without discrimination and regardless of income. For certain programs, we may provide services for younger adults with disabilities.

We serve the 54 towns of Central Vermont: all towns in Washington, Lamoille, and Orange Counties (except Thetford), as well as the towns of Bethel, Hancock, Granville, Pittsfield, Rochester, Royalton, Sharon, and Stockbridge.

For more information, please visit: www.cvcoa.org



Southwestern Vermont Council on Aging (SVCOA) serves adults 60 and older living in Southwestern Vermont who are at risk of losing their independence without additional support. SVCOA offers a range of services from a senior companion program, case management, money management programs, nutrition services, caregiver support services, transportation, State

Health Insurance Program (SHIP), and more!

For more information, please visit: www.svcoa.org



Local Resources Cont.



Dementia Family Caregiver Center

The UVMHC Dementia Family Caregiver Center (DFCC) is dedicated to the care and support of family caregivers, and provides a pathway to resources for families caring for those with Alzheimer's disease and dementia. The DFCC provides comprehensive consultations and programming to educate, build skills and support families caring for people with dementia. We help families identify available resources, such as therapeutic caregiver groups and mentoring programs. For more information regarding the services below please contact: DFCC@uvmhealth.org

CONSULTATIONS

Including dementia education, information about community resources, assistance with issues relating to caregiving, future care planning, grief and loss.

THERAPEUTIC GROUPS TEACH

For family members who are new to caregiving, we offer **TEACH**, a group program for up to seven members. **TEACH** (Training, Education, and Assistance for Caregiving at Home) is a therapeutic group that meets for 90 minute sessions for 4 consecutive weeks and is led by a trained mental health professional. Group sessions provide education and skills training for self-care, communication, resources and systems navigation, and planning for the future. **TEACH** is open to any family member who provides care to a family member diagnosed with dementia. The **TEACH** program utilizes a unique structured model of supportive interaction, information sharing and problem solving. An intake session with a clinical social worker may be needed prior to registering for this group.

VT CARERS

The VT CARERS program consists of an 8 week group for 6 members facilitated by trained mental health professionals. **CARERS** (Coaching, Advocacy, Respite, Education, Relationship and Simulation) is designed to increase understanding of the behavioral and psychological symptoms of dementia and to address caregiver burden. Sessions are focused on problem solving skills to address practical needs and resource development, and the use of patient simulation and coaching to enhance communication skills and management of emotions. Trained simulated patients attend all group sessions. **VT CARERS** is intended for family members who have been actively providing intensive care over time. We offer separate groups for spouses or partners and for adult children caregivers. A pre-assessment interview is required to participate in the **VT CARERS** program.

PEER-TO-PEER MENTORING

The **Peer-to-Peer Mentoring** program matches experienced caregivers with caregivers new to the role. This program will provide support and guidance from someone who understand the challenges caregivers face.

WORKFORCE DEVELOPMENT

VT BRIDGES (VT Broadening Resources in Developing Gerontological Education and Social Work) is a program dedicated to broadening gerontological education in social work with UVM's Social Work Department and the UVM Center on Aging.



Local Resources Cont.

The CARERS Program for Dementia Family Caregivers

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

Fall Schedule 2024

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.

July-December 2024 CARERS and TEACH Groups:

The Dementia Family Caregiver Center is currently offering 2 CARERS groups and 2 TEACH group through telemedicine, via a HIPPA compliant ZOOM video platform. These group are intended for family members who have been actively providing intensive care to a family member with dementia. We offer separate CARERS groups for spouses and adult children.

Logistical Information

CARERS Care Partners /Spouses: Friday September 27-November 11, 2024. Time: 1:00-3:30.
Facilitators, Joan Marsh-Reed, MA, and Lori P. McKenna, LICSW.

TEACH: Tuesday October 1-22, 2024. Time: 10:00-11:30. Facilitator, Lori P. McKenna, LICSW

CARERS Adult Children: Wednesday October 30-December 18, 2024. Time: 4:00-6:00. Facilitators:
Rhiannon Champagne, LICSW and Lucas Kovacevich, MSW.

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

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.



Local Resources Cont.



HDSA Regional Support And Education Series

The Binter Center in partnership with Dartmouth-Health HD Clinic and the Huntington’s Disease Society of America (HDSA) are proud to announce the return of our regional support & education series! This series provides those living with HD and their families an opportunity to learn about topics that are important to them. This series is set to return in September 2024.

September 2024– June 2025
First Tuesday of each month
5:00 pm – 6:30 pm EST

This series is free, but registration is **REQUIRED**. To register, please go to <https://uvmhealth.zoom.us/meeting/register/Jwlfu2uqzkpHtMaH6keTV8SmKSWm7SihJXc>

For any questions please contact Brandolyn Bradley at
Brandolyn.bradley@uvmhealth.org

September 3, 2024	Welcome Back: HD 101 What is Huntington’s Disease?	Stephen Lee, MD, Dartmouth-Health
October 1, 2024	Endearing Moments Can Endure HD: Connecting with your loved one, even during later stages	Jim Pollard, MA, Author “A Caregiver’s Handbook for Advanced Stage Huntington’s Disease”
November 5, 2024	Legal & Future Care Planning	Allison Bartlett, Esq, Senior Manager, Disability Programs, HDSA
December	NO MEETING THIS MONTH	
January 7, 2025	Creating a Support Network & Respite Care Planning	Lucas Kovacevich, MSW, University of Vermont Medical Center
February 4, 2025	Advanced Directives & Living Wills	Lori Fortini, Program Leader Dartmouth Healthy Aging Resource Center
March 4, 2025	Meeting Grief & Loss with a Little-Known Progressive Illness	Kelly Farrell, MSW, ACM, Continuing Care Manager, Dartmouth-Health
April 1, 2025	Research: What’s New on the Horizon?	James Boyd, MD University of Vermont Medical Center
May 6, 2025	Behavioral Challenges Associated with HD	Rebecca Thompson, MD, Dartmouth- Health Lucas Kovacevich, MSW, University of Vermont Medical Center
June 3, 2025	How to Talk with Family Members About HD: A panel discussion with family members	Kelly Farrell, MSW, ACM, Continuing Care Manager, Dartmouth-Health



LAKE CHAMPLAIN MEMORY CAFÉ



BINGO

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THE CAFE MEETS THE 2ND TUESDAY OF EVERY MONTH

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Local Resources Cont.

Movement Disorders Program Offerings

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

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.

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:

Saint Albans: Emily Houston at Emily.houston@med.uvm.edu

Williston: Zachary Wilson at Zachary.wilson@fyzical.com

Lyndonville: Joe Allard at [802-535-4520](tel: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 at 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.

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.



Local Resources Cont.

Movement Disorders Support Groups

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
"Vermont PD Support Group" (For PWP & their caregivers)	Monthly 2 nd Saturday 1 pm – 2:30 pm	Virtual Group Offering	M Sara McMahon movementforparkinsons@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)
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 linda-ichrane@gmail.com (845)-849-6562

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

National Resources

Living well with a movement disorder means getting the support you need, not only from your health care providers, but from national organizations that specialize in your particular movement disorder. The following are national organizations that can help provide the resources and support you may need to help you feel empowered about your disorder.



Founded in 1988 as a 501(c)3 non-profit organization, the **International Essential Tremor Foundation (IETF)** is guided by an executive board of directors, a medical advisory board, and an executive director

with a staff of two. The organization consists of patients, physicians, educators, health care workers, parents, relatives, friends, and volunteers. Their goal is to achieve a greater understanding and acceptance of essential tremor. The IETF facilitates educational programs that cover a variety of topics in order to educate patients, caregivers, healthcare providers, and the general public about essential tremor.



The IETF is a non-profit organization with a full-time staff and hundreds of volunteers and advocates around the world promoting research, awareness and support for essential tremor.



The IETF provides funding to researchers working to find the cause of essential tremor, better treatments and a cure.



The IETF spearheaded the creation of a National Essential Tremor Awareness Month in the United States (March), and works every year to help increase awareness among legislators and the general public.



The IETF is a proud member of the American Brain Coalition (ABC), Cures Acceleration Network (CAN), Genetic Alliance, Midwest Neurological Coalition, and many other health policy organizations ensuring ET stays in the forefront of scientific conversation.



The IETF provides free educational information and materials to everyone, to help educate healthcare providers, patients and their families on the latest advancements and options.

For more information please visit, www.essentialtremor.org.



Tremor Action Network (TAN) is a 501(c)(3) public benefit organization founded in 2003 by people diagnosed with essential tremor, cervical dystonia, and Parkinson's Disease. TAN is dedicated to providing services like one-on-one support and guidance to patients, family members, and

caregivers. Their mission is to spread awareness of tremor by advocating for a cure through research.

Goals and Objectives

Awareness Educate the public about the millions of children and adults worldwide afflicted with tremor.

Advocate Inform policy makers, healthcare professionals and the media of the quality of life challenges faced by those with movement disorders.

Research Support and promote innovative diagnostic technologies and translational research.

For more information please visit: www.tremoraction.org/resources/

National Resources Cont.



The Huntington's Disease Society of America (HDSA) is a nonprofit organization dedicated to improving the lives of everyone affected by Huntington's disease. From community services and

education to advocacy and research, HDSA is the world's leader in providing help for today, hope for tomorrow for people with Huntington's disease and their families. In the battle against Huntington's disease no one fights alone. The Frederick C. Binter Center for Parkinson's Disease and Movement Disorders at the University of Vermont Medical Center is proud to be an HDSA designated Center of Excellence. **For more information please visit www.hdsa.org**



The Huntington's Disease Youth Organization is an international non-profit supporting, educating, and empowering young people up to 35 years, impacted by Huntington's Disease (HD). Their aim is to provide a safe place to support, educate & empower young people & their families through a number of online and in-person resources.

Support

Our mission is to make sure that no young person has to suffer the impact of Huntington's Disease alone. We have support groups where you can have conversations with other young people who know what you're going through. We provide professional support and can help connect you to professionals in the community.

Educate

Huntington's Disease is a complicated disease which is tough to understand and manage. There's a lot happening in the complex world of HD research. HDYO provides educational resources in easy-to-understand formats. Our aim is to help young people and their families understand more about the disease and hear the latest in research news in simple language.

Empower

We want to ensure all young people impacted by HD are empowered to help themselves and their families. We want to erase the stigma of the disease. We encourage young people to be their own advocates by sharing their stories and connecting with others in the community.

For more information, please visit www.hdyo.org



More than HD is an online resource center helping those diagnosed with Huntington's Disease (HD) understand more about Chorea, the defining symptom of HD. More than HD provides resources to understand more about the disease, research treatment options, and being a caregiver. **To learn more, please visit www.morethanhd.com.**



National Resources Cont.



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, neurological disorder. Founded in 1961, APDA has raised and invested more than \$282 million to provide outstanding patient services and educational programs, elevate public awareness about the disease, and support research designed to unlock the mysteries of PD and ultimately put an end to this disease. To join in the fight against PD and to learn more about the support APDA provides nationally through their network of Chapters and Information & Referral (I&R) Centers, as well as our national Research Program and Centers for Advanced Research, **please visit at www.apdaparkinson.org**.



The Davis Phinney Foundation has brought to life some of the most important programs, research, content, and events for those affected by Parkinson's. Their community includes people living with Parkinson's, Parkinson's care

partners, families and friends of those living with Parkinson's, physicians, and Parkinson's allied health professionals. Their mission is dedicated to helping people with Parkinson's live well today.

Their programs include:

- Care Partner Training
- PD Self®
- Pedaling for Parkinson's™
- The Parkinson's Podcast™

The Davis Phinney Foundation also provides resources on clinical trials, including providing funding to over 30 research studies focused on exercise, nutrition, gait, speech, telemedicine, alternative therapies, and other interventions that affect quality of life.

For more information, please visit www.davisphinneyfoundation.org



Parkinson's Connect Live is a free program that provides Zoom calls for people with Parkinson's disease and caregivers. Sessions focus on conversation, social connection, and quality of life. Parkinson's Connect Live sessions

are a great place to meet others on the Parkinson's journey, practice communication skills, and learn more about the disease.

Speech pathologists host sessions; however, they do not provide speech therapy. Parkinson's Connect Live sessions include topics on navigating life with PD, sharing experiences, caregiver support, message banking, and more. Parkinson's Connect Live is a free program that provides Zoom calls for people with Parkinson's disease and caregivers. Sessions focus on conversation, social connection, and quality of life. Parkinson's Connect Live sessions are a great place to meet others on the Parkinson's journey, practice communication skills, and learn more about the disease.

For more information, please visit: www.pdconnectlive.com

National Resources Cont.



The Parkinson's Foundation (PF) was formed by the merger of the National Parkinson Foundation (NPF) and the Parkinson's Disease Foundation (PDF). In June 2017, the Foundation marked the 200th anniversary of the publication of, "An Essay on the Shaking Palsy," by James

Parkinson and the 60th anniversary of the Parkinson's Foundation.

Their core mission is to:

- Provide life-changing support to people living with Parkinson's and their caregivers
- Fund game-changing research on treatment and care
- Convene the best minds from every corner of the global Parkinson's community to find new approaches that enhance care and move us closer to a cure.

For more information, please visit: www.parkinson.org



The Michael J. Fox Foundation is dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today.

The Michael J. Fox Foundation (MJFF) exists for one reason: to accelerate the next generation of Parkinson's disease (PD) treatments. In practice, that means identifying and funding projects most vital to patients; spearheading solutions around seemingly intractable field-wide challenges; coordinating and streamlining the efforts of multiple, often disparate, teams; and doing whatever it takes to drive faster knowledge turns for the benefit of every life touched by PD.

For more information, please visit: www.michaeljfox.org



Parkinson & Movement Disorder Alliance (PMD Alliance) is an independent, national nonprofit dedicated to providing opportunities for people to learn, live more

fully and spark meaningful connections around them. PMD Alliance provides resources and education to people in 50 states and more than 40 countries. Their Movement Disorder Care & Support Ecosystem © serves as a guiding star and catalyst for action.

The ecosystem is made up of five unique networks:

- The Therapy Network
- The Medical Network
- The Community Network
- The Family Network
- The Companion Network

For more information, please visit: www.pmdalliance.org



National Resources Cont.



Parkinson's Resource Organization is dedicated to improving quality of life for families and individuals affected by Parkinson's disease through education, support, and practical resources. To address the acute needs of the

Parkinson's community – namely caregiver support and resource pooling – they built several core programs:

Support Groups Through dedicated in-person **support groups** for caregivers and people with Parkinson's, they distribute new information quickly and build a community network that teaches and learns from itself.

Wellness Village Resource Directory The Wellness Village is a free, virtual, vetted, digital resource directory of the best available providers and services within the Parkinson's world, designed to ease the research burden and introduce constituents to a wide range of holistic and practical support services to navigate Parkinson's and maximize quality of life. (Cont. on next page)

Memorial Wall A virtual place to hold the memory of someone who lived with Parkinson's or Parkinsonisms and their family members, caregivers, and friends who were touched by Parkinson's. A virtual place where family and friends can grieve and heal, gain solace and understanding, and virtually 'visit' their loved one. A virtual means of announcing the passing to a greater number of people than can otherwise be accomplished through a tangible publication.

For more information, please visit: www.parkinsonsresource.org



Caring is a national resource aimed to help improve the lives of older adults by providing free customized referrals and guidance. Their mission is to help as many older adults, families, and caregivers navigate the complex system of in-home support, assisted living, and caregiver resources.

 <p>Relevant information and support</p> <p>We offer comprehensive directories with information about independent living, assisted living, memory care, in-home care, skilled nursing, and other senior care services.</p>	 <p>Industry-leading reviews program</p> <p>We host hundreds of thousands of consumer reviews to help families research and select senior living communities and in-home care agencies.</p>	 <p>Free Customized Referrals and Guidance</p> <p>Our expert Family Advisors help to match specific services, products and providers that meet a family's needs, budget and preferences.</p>	 <p>Trusted Experts</p> <p>Our nationwide team of senior care professionals are among the most highly trained, highly skilled and knowledgeable experts in senior care.</p>
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For more information, please visit: www.caring.com.

Clinical Research at the Binter Center

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



<https://www.topazstudy.org/>

The TOPAZ study is done from your home!

TOPAZ is a clinical trial that will test if a medicine called zoledronic acid can prevent fractures and decrease the risk of dying in people with Parkinson's or parkinsonism.

You can join if you...

- **Have Parkinson's or parkinsonism**
 - **Are 60 years or older**
 - **Have not had a hip fracture**



ORMIS-PD STUDY

(Ontology-based, Real-time, Machine learning Informatics System for Parkinson's Disease)

We are looking for people to participate in this pilot research study of a novel investigational data and machine learning-based tool designed to augment clinical diagnosis of Parkinson's disease (PD) and to predict the course of an individual's PD based on the signs and symptoms captured using the ORMIS-PD tool.

This study only requires one visit and is only observational in nature with no change in treatment or testing needed. During the visit, we will ask you questions about your health, medications, and environment. Additionally, there will be a physical and neurological exam that includes questionnaires.

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

- You have been diagnosed with Parkinson's disease
- You are 40 years or older in age

For more information about the study, please contact the lead investigator, Dr. Deepak Gupta, or the study coordinator, Emily Houston at 802-656-8974.



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



GyroGlove™ is a non-invasive, drug-free, wrist worn device designed to tackle impairments of essential tremor.

Research Description & Purpose:

Researchers at the University of Vermont Medical Center want to find ways in stabilizing hand tremors due to essential tremor during activities of daily living with a wearable device. Research is always voluntary!

Would the study be a good fit for me?

This study may be a good fit for you if you are:

- 18 years of age or older
- Have been clinically diagnosed with essential tremor
- Have either tremor of one or both hands predominantly involving hand as well as forearm
- Have a score of = 2 in ADL activities 2, 3, 6 & 8 of the TETRAS ADL subscale (TRG, Sep 2021).

Clinical Research Cont.



- Tremor in at least one hand (dominant hand) causing water spillage during drinking
- Ability to speak and read in the language that the study documentation has translated to
- Ability to provide written, informed consent to participate in the study
- Capacity to complete self-report outcome measures in the language that the trial documentation has been translated to

What would happen if I took part in the study?

If you decide to take part, you will be asked to attend three (3) on-site appointment sessions and to perform 3 self-assessments at home or where most convenient to you.

The first appointment is a screening appointment aimed at confirming your eligibility for the study. It will last around 40-60 minutes and it will be performed at University of Vermont Medical Center.

The second and third appointments will be the assessment session which will last between one and a half and two hours and will be performed at University of Vermont Medical Center. Between second and third appointments, there will be two weeks during which you will be given a GyroGlove™ to use at home when needed but, for at least two hours per day.

The self-assessments will be conducted by you at home or where most convenient for you and will require approximately 30 minutes to complete.

Volunteers who take part in the study will receive reimbursement of traveling costs up to \$30 per visit or as per recommendation received from the Institutional Review Board (IRB).

Specify Location of Research:

This research will take place at University of Vermont Medical Center located at 1 South Prospect Street, Burlington, VT 05401.

Contact Information:

To take part in above study or for more information please contact Dr. James Boyd at 802-847-4589 or study coordinator Mary Collins at 802-847-1597

Clinical Research Cont.



The University of Vermont Medical Center in partnership with the University of Vermont, is currently involved on over 1,000 active clinical research trials in various specialty areas. This allows us to offer our patients immediate access to treatments not available anywhere else. Our discoveries not only improve care for our patients at the UVM Medical Center, but across the country and around the world.

Any research opportunity that we offer to our patients has been approved by our Institutional Review Board which demands the highest level of ethical behavior, transparency, and protection of patient safety and privacy.

Ask your doctor if there are any available research studies for your condition. Every clinical trial has specific safety criteria that define which patients can participate in the trial.

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!

If you have questions about research opportunities,
please contact our Research Coordinators:
Emily Houston, 802-656-8974 Emily.houston@med.uvm.edu
Mary Collins 802-847-1597 Mary.collins@uvmhealth.org

BINTER CENTER NEWSLETTER

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Support the Binter Center

The Binter Center's budget is focused on providing top-notch clinical care, but the income from clinical care does not provide a margin for innovation and program development. This is why charitable gifts to support the Binter Center's educational, research and programmatic priorities are so important.

With your support, we at the Binter Center can continue to develop and expand *local* programs and services, participate in the latest clinical research, and provide education to fellow clinicians, students, and the community. Thank you for considering making a contribution!

Donate online at UVMHealth.org/binter or call **802-656-2887**.

