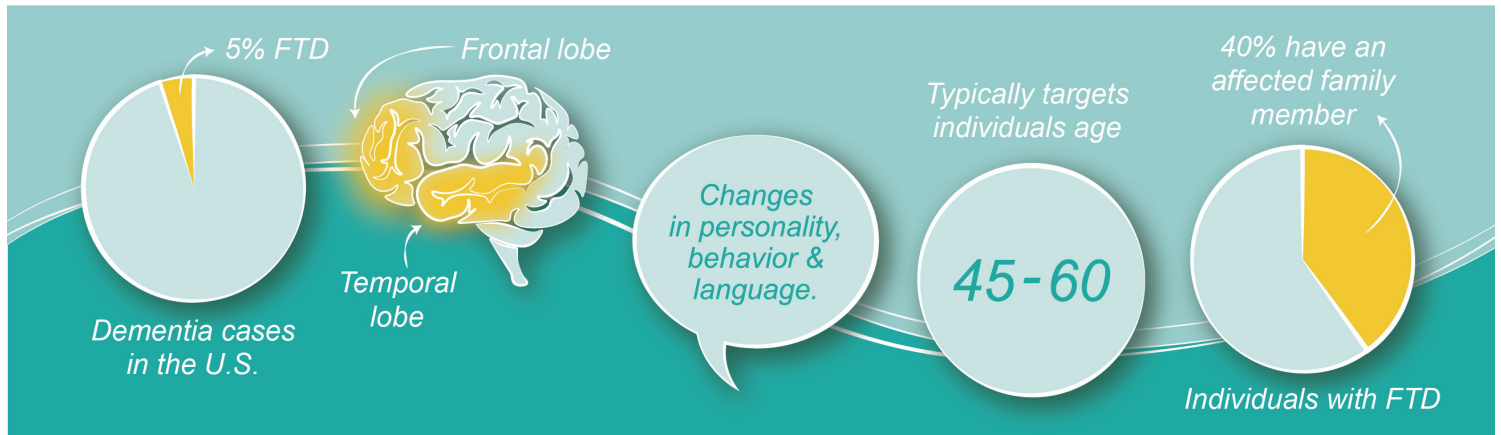


## A Research Participant's Donation Sparks Needed Research into an Understudied Form of Dementia



Research into priority areas of dementia is made possible at our center by generous donor gifts. This past winter, we received a generous donation from the family of one of our research participants to further study a less common type of dementia, frontotemporal dementia or FTD.

Our research participant had inherited FTD from her father. After she died from the disease last winter, her family gifted the donations made at the funeral to our center to further study frontotemporal dementia.

FTD accounts for 5% of all dementia cases in the United States. The primary course of the disease damages the frontal or temporal lobes of the brain which results in significant changes in personality, behavior, and language ability. FTD is a unique dementia in that it targets younger individuals, typically between ages 40 and 65. It is also highly heritable. Approximately 40% of individuals with FTD have an affected family member.

A major research emphasis at our center is to study the less common types of dementia, including the causes and treatments of the various forms of FTD. Director Dr. Henry Paulson's lab directly studies FTD at the molecular, cellular, and human neuropathological levels. These new funds will allow his laboratory to:

- Explore the biological pathways by which harmful gene products in a specific type of FTD are handled in neurons and other cells
- Understand why a class of proteins known as ubiquilins are associated with FTD
- Generate critically important genetic information on the many FTD brains donated at the Michigan Brain Bank. This genetic information increases the value of these priceless brain tissues for researchers as they seek to understand the causes of FTD.

We are grateful to this participant and their family for generously supporting

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*Our goal is to make advances in our understanding and treatment of FTD. We hope to turn this from a disease in which we are beginning to understand the genetic underpinnings of the disease to one in which we have treatments that slow or alter its course. - Dr. Henry Paulson.*

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our research. We look forward to furthering our research in FTD due to their gift, and to move the field forward in our understanding of this set of diseases.

Donations big and small are important to our work as a center and to further dementia research. If you are interested in contributing to our center, please visit [alzheimers.med.umich.edu/support-us](http://alzheimers.med.umich.edu/support-us) to learn of opportunities, or contact Allison Clark, Assistant Director of Development, Neurosciences, at [ajmayer@umich.edu](mailto:ajmayer@umich.edu) or 734-763-1638.

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# Note from the Director

As a member of the External Advisory Board of the NIH-funded Alzheimer's Disease Sequencing Project, I had the privilege this week of listening to a super-talented group of scientists from across the country describe the latest genetic discoveries in Alzheimer's and related dementias. These scientists are fearless in applying the newest technologies to hunt for the genetic underpinnings of dementia, with the goal of identifying therapeutic targets that can slow it down.

What did I take home from this two-day meeting?

First, hundreds of the very best and brightest scientists are devoting themselves to tackling this disease. That's a comforting thought.

Second, scientists across the field have come to realize that dementia is remarkably complex. Focusing on a single factor like amyloid doesn't make sense anymore. While I remain hopeful that we will find a use for anti-amyloid therapies (like aducanumab) in Alzheimer's, too much focus on amyloid will hold us back. Genetic discoveries are telling us that much more is going on. We also need to explore immunological and inflammatory pathways, investigate the link between vascular risk factors and dementia, and determine how genes and environment together influence brain health.

Third, we will only succeed in finding therapies if we build better pipelines of communication across scientific disciplines. The answers to disease will come from the convergence of ideas and technologies brought to the problem by a diverse range of investigators.



*Henry Paulson, M.D., Ph.D.*

These “take homes” left me reassured that we are doing the right things here at the Michigan Alzheimer's Disease Center. For example, our center exists precisely to foster communication across our great state and throughout the country. And our center's “beyond amyloid” theme embraces the complexity of dementia.

That point is underscored time and again in this newsletter. Articles highlight our work investigating the myriad faces of dementia -- from frontotemporal dementia to Lewy body dementia to vascular dementia, and, yes, Alzheimer's too. An article also describes our efforts to understand the causes of cognitive impairment in African Americans, in whom the causes of dementia remain understudied. While Alzheimer's and related dementias are a complicated set of diseases, I am pleased to say that our team and the field are moving the needle forward, and we couldn't do it without you.

A handwritten signature in black ink, appearing to read "Henry Paulson".

**Henry Paulson, M.D., Ph.D.**

Lucile Groff Professor of Neurology  
Director, Michigan Alzheimer's Disease Center  
Interim Co-Director, Michigan Neuroscience  
Institute

# An Update from our Detroit Advisory Council

Our Detroit Advisory Council has been hard at work supporting our research and retention efforts in Detroit's African American community. Earlier this fall, we welcomed several new members to our council. Our council membership now includes:

- James Bridgforth - Healthier Black Elders Center
- Lena Nichols - Community Champion
- Miles Maxey - Community Champion
- Patricia Mullin - Healthier Black Elders Center
- Patricia Rencher - Urban Aging News
- Ronald Taylor - Detroit Area Agency on Aging
- Willie Manning - Community Champion



*Detroit Advisory Council members (Back row, left to right): Willie Manning, Pat Rencher, Jim Bridgforth and Miles Maxey. (Front row, left to right): Danielle Davis, Pat Mullin and Lena Nichols.*

The aim for this council is to expand research participation, enhance retention, and educate on the importance of brain donation in the African American population.

The council began new efforts in support of this mission in the fall when they reviewed our Research Volunteer Form for inclusivity and accessibility by the African American population. Our center uses the RVF to gather initial information on those potentially interested in participating in center research. These efforts will ensure this pivotal form in the research recruitment process will be understandable and relatable to the population we hope to serve.

This winter, the council also began a comprehensive analysis of our feedback procedures and materials for sharing with our research participants the results of their Annual evaluation (e.g. their performance on memory tests, their results for diagnostic and imaging tests). This process, led by Annalise Rahman-Filipiak, Ph.D., is new to our center and one of our key ways of giving back to participants in appreciation of their volunteer efforts. The council took a close look at the procedures we follow for presenting testing feedback to our participants, as well as the resources that support these efforts to ensure that our efforts were supporting the retention of our African American participants.

Our Detroit Advisory Council Lead, Danielle Davis, has also transitioned to working full time from our Detroit site at the U-M Detroit Center to further support the community.

The council continues to support our work through the sharing of community events, resources, and groups that will help us learn how to better connect to the Detroit community. Through our council, and our team members, we hope our efforts will begin to embed us into the Detroit community to further educate and support the development of cures for all communities.

## *Why is African American participation in research so important?*

African Americans have a higher rate of vascular disease and are two times more likely to develop Alzheimer's disease than whites. However, their engagement in dementia research has faced numerous barriers at the systemic, community and institutional levels. Prior examples of unethical research practices have created some understandable wariness about study participation, and many are not aware of the potential community benefits of engaging in dementia-related studies. It's extremely important to have representation from different groups when it comes to research to support the development of interventions and cures that support all populations.

Acknowledging and understanding the history of African Americans' participation in research is important in our work, and a driving factor behind the creation of our Detroit Advisory Council. We hope our work in the Detroit area will help begin to address community concerns and improve participation so that interventions and cures can be inclusive to all.

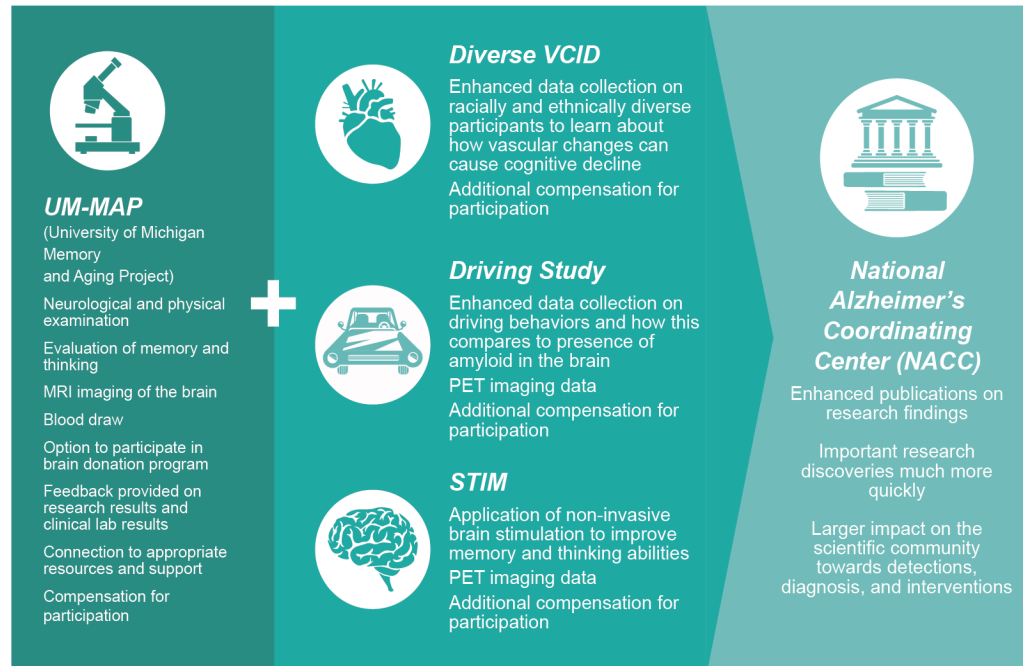
*To learn more about the importance of minority participation in research, please find a video by our Minority Outreach Coordinator, Danielle Davis at [michmed.org/7VBn9](https://michmed.org/7VBn9)*

# Center Co-Enrollment Opportunities Enhance Research Discoveries Nationally

The structure of our Center is built around supporting the work of the University of Michigan Memory and Aging Project, or UM-MAP. This study follows participants annually, with data from our comprehensive evaluations shared with a national database that includes participants from over 30 centers across the U.S. We've called UM-MAP the "bread and butter" of our Center activities in previous issues of this newsletter. While this continues to be true, rapid growth in recent years and increased collaboration with other NIH-funded Alzheimer's Disease Research Centers (ADRCs) has created various opportunities for UM-MAP participants to take part in additional research projects at the same time as their UM-MAP visit through a co-enrollment process.

Co-enrollment in research studies, simply put, means that participants will join more than one research study at the same time. At the Center, we use the term co-enrollment when referring to joining our longitudinal study, UM-MAP, along with another study that the participant is eligible for and finds interesting. There are many benefits to co-enrollment for participants and researchers. For participants, this means that they can participate in multiple studies at the same time or in fewer study visits than if they joined the studies at different times. Since much of the data collection for each study is similar, participation takes less time, helps more researchers, and often involves multiple monetary incentives. There is also an opportunity to receive feedback on additional biomarker data that wouldn't be possible if participating in just one study.

For researchers, co-enrolling participants is incredibly helpful because oftentimes different studies involve gathering much of the same information – such as imaging scans, neuropsychological test results, or blood test results – and if a participant



is participating in multiple studies, this information can be shared between the study teams. This is more cost effective and less burdensome for the research team and participants.

One of the most important benefits to co-enrollment, however, is that linking UM-MAP with additional research studies leads to the sharing of participant clinical, behavioral, neuroimaging and biomarker data, which has the potential to lead to important research discoveries much more quickly. As noted above, participant data is compiled and sent to the National Alzheimer's Coordinating Center, which holds a centralized repository of data from ADRCs around the country created to facilitate collaborative research, and is one of the largest, most comprehensive databases of its type. This, of course, has a much larger impact on the scientific community towards finding a cure to Alzheimer's disease and related dementias and in turn benefits research participants, researchers, and all who have been affected by the disease.

We have several projects recruiting participants that require co-enrollment into UM-MAP where participants can enroll in multiple studies in the same study visit. Three of these projects are featured below.

## [The Diverse Vascular Contributions to Cognitive Impairment and Dementia Study](#)

The Diverse Vascular Contributions to Cognitive Impairment and Dementia Study, or the Diverse VCID Study, is a study using advanced brain imaging and blood-based techniques to understand how vascular changes in later life cause brain injury and cognitive decline. The Diverse VCID Study is a 6-year national study of 2,250 Americans from diverse backgrounds to understand the role that cerebrovascular disease plays in developing Alzheimer's disease and other dementias. The study is led nationally by the University of California – Davis Alzheimer's Disease Center and our Center is one of 12 sites.

We are interested in enrolling African American participants between age 65 and 90 with either normal cognition and memory concerns or a diagnosis of mild cognitive impairment (MCI). Participants will be seen at the University of Michigan Ann Arbor and/or University of Michigan Detroit Center annually and will be asked to participate in a testing visit as well as a blood draw and brain scan.

Those interested in the Diverse VCID study can contact the study team at 734-615-8378 or daviscd@med.umich.edu to get started.

### The Driving and Physiological Responses Study

Driving is an activity that many people routinely engage in, and new automobile technologies may allow researchers to identify driving behaviors that signal whether an individual is at risk for developing cognitive difficulties or is in the very early stages of cognitive decline. The Driving and Physiological Responses Study, or Driving Study, is looking at whether certain driving behaviors in day-to-day life or in a laboratory can differentiate individuals who are

cognitively healthy and those who have cognitive difficulties. The study is led by Center Associate Director, Dr. Bruno Giordani.

We are interested in enrolling individuals aged 65 and older who are either cognitively healthy or have a diagnosis of MCI, have a valid driver's license, drive at least one per week, and drive a car that is model year 1996 or newer. Driving data is kept confidential and is used for research purposes only.

Those interested in the Driving Study can contact the study team at 734-232-0128 or cal-npresearch@med.umich.edu to get started.

### The Stimulation to Improve Memory Study

The Stimulation to Improve Memory Study, or STIM Study, is a non-pharmacological clinical trial evaluating a form of non-invasive brain stimulation called transcranial direct current stimulation (tDCS). The study is investigating whether tDCS changes the way different brain regions communicate and if it improves memory and thinking abilities in older adults with MCI and Alzheimer's

disease. Participants take part in up to 30 sessions of tDCS while focusing on old memories and will receive brain imaging scans before and after these sessions. The STIM Study is led by Center Clinical Core Lead, Dr. Benjamin Hampstead.

*Learn more about the other research studies we have available at [alzheimers.med.umich.edu/research](http://alzheimers.med.umich.edu/research)*

We are interested in enrolling individuals aged 55 and older with a diagnosis of MCI or Alzheimer's disease who are English speaking and stable on medications for at least 4 weeks.

Those interested in the STIM Study can contact the study team at 734-936-7360 or schlst@med.umich.edu to get started.

We have additional options for those interested in volunteering for research and a full list of our currently enrolling research studies can always be found on our website at [alzheimers.med.umich.edu/research](http://alzheimers.med.umich.edu/research).

## *Would you or a family member be interested in brain donation?*

Brain donation is one of the greatest gifts to further dementia research.

Brain autopsies are an important source of information about how disease affects the brain's anatomy. This information is used to direct future research into the causes of memory loss, their progression over time, and clues about effective treatment approaches. What we know today has only been possible because of the commitment of patients and research participants who donate their brain to science.

When a patient or research participant passes away, our staff work alongside families to ensure wishes are met, loved ones are cared for thoughtfully, and funeral arrangements are accommodated.

If you are interested in learning more, contact Matthew Perkins, Michigan Brain Bank Coordinator, at 734-647-7648 or [UMHSbrainbank@med.umich.edu](mailto:UMHSbrainbank@med.umich.edu).



# Wellness Initiative Launches Online Learning Platform to Support Caregiver Wellbeing

*“One thing that you recognize as you become more present in caring for someone else, the priorities of your time and energy are very easily shifted to them and remembering to prioritize yourself is important. Your own health and wellness are paramount to our ability to care for others.” - Carol D., caregiver participating in our wellness programs*

We are thrilled to launch the CALM Connections online learning platform for dementia family caregivers. Over the past decade of offering our wellness programs to family caregivers, our Wellness Initiative has learned first-hand some of the challenges and barriers that caregivers face when caring for someone they love. While we've offered a variety of in-person programs to those in and around the Ann Arbor area, sharing the skills developed in our programs in a new, virtual way was

always an opportunity we hoped to meet to provide more caregivers with the resources they need to thrive. While workshops and presentations may serve helpful for learning new skills, we've often found that caregivers often miss the opportunity to practice these new skills or connect with others who may have gone through similar experiences. CALM Connections makes it possible for all caregivers to learn online, and connect with the wisdom and experiences of others in a

Visit CALM Connections at [calmconnections.med.umich.edu](http://calmconnections.med.umich.edu)

safe and private way. This is a unique initiative to support family caregivers, and we are pleased to have the opportunity to share these resources with the larger dementia community.



Working to help caregivers feel connected and prepared with the tools they need to thrive

A long-term and sustainable approach to wellbeing includes navigating the inevitable rough patches and building the capacity to navigate through uncertainty, uncomfortable changes, feelings, and difficult decisions. CALM Connections aims to foster this approach to wellbeing through developing greater caregiver confidence to navigate the down cycles and maintain self care practices. We've found that caregivers need a dedicated outlet, reminders, and a sense of community to maintain their health for a resilient and enjoyable life. CALM Connections was created to bring the emotional and mental wellbeing needs of the caregiver to the forefront of daily life and care planning. When strong wellness habits are firmly in place, a

caregiver is better equipped to handle unnecessary distress and isolation and support the family and person in their care.

Promoting connection to avenues of support, elevating the importance of community, and eliminating program barriers

The site content and features in CALM Connections are structured to support participants in learning, prioritizing, and practicing skills for their wellbeing in their daily lives. With doorways to live programming opportunities in each session, caregivers can choose their own wellness path and best dose of self-paced information and support without feeling pressure to officially “join” a group.

CALM Connections contains a library of sessions as part of an expanding

learning curriculum. Sessions are organized around topics which provide each participant with layers of information and opportunities for reflection and practice. Sessions include navigating the emotional terrain of difficult decisions, grieving through changes and loss, implementing, adjusting, and maintaining boundaries, as well as mindfulness-based approaches to care.

Each session highlights practical skills while highlighting actionable next steps and clarity through complex issues. While caregivers are busy and overwhelmed, building these new habits and creating more space for self-care takes time and practice. This platform allows caregivers to revisit sessions and modules to practice, adjust, or elaborate on these skills.

Each session includes audio recordings, handouts, videos, meditations, and recommendations for further exploration in each topic area. Access to program recordings and

places for writing and saving personal notes-to-self are also available.

### Designed to develop wellness strategies and stress resilience skills to support caregiver wellbeing

CALM Connections provides wellbeing content and peer wisdom to help caregivers prioritize their own needs and health while caring for others. Because the caregiving journey presents unique challenges over many years, the vision of CALM Connections is to offer ongoing education, training, and resources to consistently support a caregiver's wellbeing needs over time. Maintaining one's own wellbeing while caring for a loved one with dementia is difficult and requires continuous commitment, tailored environments, and reinforcements. CALM Connections provides encouragement and ongoing opportunities to regularly return to one's self-care. It is a space for growing, healing, and finding reassurance while building skills for

resilience through easy to access sessions in a self-paced format.

We are enthusiastic to be able to offer this service to the caregivers we work with, and new caregivers who may be interested in learning more about developing stress resilience and wellness skills. We hope to continue to develop new programs and materials here on CALM Connections to meet the needs of family caregivers and that this will be a place to visit and refuel between our in-person groups, other support groups, or other dementia programming. Like a bookmark placed in the journal of one's personal wellbeing, it's a way to stay closer to a deeper, calmer and more grounded sense of self through it all.

*Learn more about current caregiver programs at [alzheimers.med.umich.edu/wellness-initiative](https://alzheimers.med.umich.edu/wellness-initiative)*

## Lewy Body Dementia Support Group Expansion and Transition to In-Person Groups

At the beginning of the COVID-19 pandemic, many of the facilities where we met for our Lewy body dementia (LBD) support groups closed. Our Rinne LBD Initiative team and support group members quickly adjusted to holding these support group meetings virtually. While this has been a wonderful way to remain connected over the past two years, we know that in-person meetings offer community and support that is difficult to replicate in the virtual setting.

After two years of meeting in a virtual format, we are excited to announce that our in-person support groups resumed in April. We offer in-person groups in Ann Arbor, Lansing, Harbor Springs, and Boyne City.

Due to our continued growth, and the expanded reach we experienced from meeting virtually, we are also excited to announce our support group expansion to Grand Rapids. Our hope with this expansion is to meet the needs of those living with LBD on the west side of the state who don't currently have an in-person meeting close to home.

We hope this effort will continue to expand our reach of dementia support and complement our mission of the Rinne Lewy Body Dementia Initiative. This aligns with our goals to provide education, support, and research opportunities across the state, and we hope this fosters a closer, ongoing relationship with residents and aging organizations in the Grand Rapids



area. More details will follow on this exciting expansion.

To hear more about these updates as they develop, consider subscribing to our Rinne LBD Initiative e-newsletter at [alzheimers.med.umich.edu/education-outreach](https://alzheimers.med.umich.edu/education-outreach).

Are you interested in joining one of our current support groups? Visit [alzheimers.med.umich.edu/lbd](https://alzheimers.med.umich.edu/lbd) for support group dates and locations.



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## Learn About How We Store Your Data, Other Programs at Our Center, and the Latest Information on Alzheimer's Disease Treatments in our YouTube Video Library

This past summer, our team worked to summarize the many facets of our work into a series of short videos now hosted on our center's website and the Michigan Medicine YouTube channel. Whether you're a research participant interested in knowing how we securely store your data, a member of our support groups interested in learning more about getting involved in research, or a health professional wanting more details about our center's activities, we believe you'll find these helpful and educational.

A summary of our video collection is available below. Visit [michmed.org/YDKAV](http://michmed.org/YDKAV) to view the video library.



- ▶ ***Alzheimer's Disease Treatments*** by Judy Heidebrink, M.D., M.S.
- ▶ ***Why You Should Participate in Research*** by Arijit Bhaumik
- ▶ ***How We Protect Participant Data*** by Jonathan Reader, M.S.
- ▶ ***About the U-M Memory and Aging Project*** by Holly Bunker, M.A.
- ▶ ***The U-M Memory and Aging Project Visit*** by Stephen Campbell, LMSW
- ▶ ***The MiNDSet Registry*** by Kate Hanson, M.A.
- ▶ ***Minority Representation in Research*** by Danielle Davis
- ▶ ***Our Caregiver Programs*** by Laura Rice-Oeschger, LMSW
- ▶ ***Our Programs for People Living with Dementia*** by Ashley Miller, M.P.H.
- ▶ ***The Rinne Lewy Body Dementia Initiative*** by Renee Gadwa, M.B.A.
- ▶ ***How to Get Involved with the Michigan Alzheimer's Disease Center*** by Erin Fox

### *About Us*

The Michigan Alzheimer's Disease Center is dedicated to the discovery of new ways to diagnose, treat, and prevent Alzheimer's disease and related dementias. We promote state-of-the-art clinical care, conduct memory and aging research, and provide education, support, and wellness programs.

#### Join us at our upcoming events

Our full calendar of events is at [alzheimers.med.umich.edu/events](http://alzheimers.med.umich.edu/events).

#### Find resources, support, and more by following us on social media

  @umichalzheimers

#### Visit our website at

[alzheimers.med.umich.edu](http://alzheimers.med.umich.edu)

#### SUPPORT

Gifts from generous donors are critical to support our work. If you are interested in giving, please contact Mike Harders at [miharder@umich.edu](mailto:miharder@umich.edu) or 734-763-1402. A variety of gifting opportunities are also available at [alzheimers.med.umich.edu/support-us](http://alzheimers.med.umich.edu/support-us).

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