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 other dementias. We promote state-of-the-art clinical care, conduct memory and aging research, and provide education and wellness programs.

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CENTER WEBSITE
alzheimers.med.umich.edu

MICHIGAN HEALTH BLOG
healthblog.uofmhealth.org

Interested in research participation?
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Questions about education or wellness programs?
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Interested in making a donation?
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Center enrolls research participants at first-ever mobile site in Port Huron

As a statewide Center, one of our key goals is to expand dementia education and research across Michigan. We succeeded in educating diverse areas of Michigan—traveling to speaking engagements on the east and west shores, rural areas in the middle, and even the Upper Peninsula. Despite this success in widespread education, up until a few months ago we did not have the resources to expand research opportunities beyond the Ann Arbor and Detroit areas. That changed this past fall.

In October, thanks to the generous efforts and funds of our community partner and donor, Marcia Haynes, Center staff traveled to Port Huron to enroll interested research participants into the University of Michigan Memory and Aging Project (UM-MAP). For the first time, the Center’s research efforts took place in a mobile, community-based setting, forging great potential for research recruitment efforts for years to come.

This initiative would not have been possible without the determination of Haynes and the local community group she created, the Dementia and Alzheimer’s Resource Committee (DARC). Haynes—who was caring for her husband with Alzheimer’s disease at the time—and the committee worked diligently to educate the Port Huron community on the importance of clinical care, early detection, caregiver support, and research participation before the Center became involved in expanding these efforts in 2015.

Over the course of several years and combined education efforts between the DARC and our Center, local interest began to grow around research participation. With travel to Ann Arbor being a significant barrier, Haynes and the DARC identified an appropriate location and generously funded lodging and expenses to bring Center research staff to Port Huron.

“It took us many years to get everyone here to talk about dementia and understand the importance of research, but we made it happen,” says Haynes about the stigma associated with diagnoses of dementia and hesitation to participate in research studies.”

Over four days in Port Huron, 10 participants were enrolled into the UM-MAP study, creating a unique cohort of participants that Center researchers would otherwise be unable to study. We look forward to following these individuals for many years to come.

We are so grateful for Haynes and the Dementia and Alzheimer’s Resource Committee for partnering with us in education and research, and thank them for making this new venture possible.
Note from the Director

Greetings from Ann Arbor!

Twice monthly, on Monday mornings, I gather with our entire Center team for a staff meeting. At each of these meetings I am reminded that the engine making this Center hum is our incredibly talented and dedicated staff. It often amazes me how much our Center can accomplish in the short time between meetings.

As I look through this newsletter, I see the footprints of that remarkable staff everywhere. From the dedicated group that trudged northeast in two vans to inaugurate our first satellite research efforts in Port Huron, to the tireless efforts of Brain Bank Coordinator Matthew Perkins, who works 24/7 to serve the wishes of patients and families who wish to donate their brains to advance research. From Research Administrator Arijit Bhaumik, who recently won the most prestigious award for research administrators at the University, to Erin Fox, who worked week after week to make the “Dementia for Scientists” curriculum a reality. From the many Research Coordinators who greet and evaluate every research participant who walks through our doors (there isn’t space here to name them all!), to the equally dedicated folks who work behind the scenes to make sure we are collecting and storing data properly.

As we enter 2019 with a growing staff, I reflect on a memorable year of accomplishments, and feel a tremendous sense of gratitude...for the hard work of a talented staff, for the commitment of our research participants, and for the opportunity I’ve had to be a part of something that is making a real difference in people’s lives.

Thank you all, and I can’t wait to see what we continue to accomplish together!

Henry Paulson, MD, PhD
Lucile Groff Professor of Neurology
Director, Michigan Alzheimer’s Disease Center
Co-Director, U-M Protein Folding Diseases Initiative
Center launches first-ever $10 million fundraising campaign

The Center publicly launched an ambitious $10 million fundraising campaign.

The goal of the campaign, the first ever for the Center, is to raise funds to conduct groundbreaking research, provide state-of-the-art patient care, enable talented faculty and fellows to advance the field, promote wellness and outreach programs, and increase public awareness of dementia and access to resources.

Director Hank Paulson, MD, expressed his confidence in the success of the ambitious campaign.

“We’re the only university in the country with top 10 schools of medicine, law, business, engineering, and public health on the same campus, providing unmatched interdisciplinary opportunities. Further, we are among the select few institutions in the country that have three National Institutes of Health-funded centers in Alzheimer’s, Parkinson’s, and aging research,” Paulson said. “We’re also formally partnered with Wayne State University and Michigan State University to better serve patients and families throughout the state of Michigan. By tapping into the power of the University’s top-ranked programs and world-class researchers, as well as collaborating with the state’s top-institutions, we are taking on Alzheimer’s disease and related dementias with a range of promising possibilities.”

The highest priority is to raise funds for groundbreaking research that seeks to identify, understand, and modulate the many factors beyond amyloid that contribute to brain dysfunction in Alzheimer’s disease and related dementias, which are understudied and present great opportunity for progress.

Another key priority of the campaign is to establish professorships that will enable us to recruit neurodegenerative disease experts who will help advance research efforts.

We are also pursuing a leading-edge, multidisciplinary approach to patient care. Providing patients with the most advanced therapies, including access to a broad range of clinical trials, is of utmost priority in the campaign.

Supporting caregiver wellness is also an integral part of our vision. In 2012, we launched wellness programs that emphasize stress resilience to ensure continued health and well-being for those with, or caring for someone with, Alzheimer’s disease and related dementias. We hope to continue this initiative and increase access to these programs for patients and families across the state.

We are committed to improving knowledge and awareness of dementia through collaborative education and outreach efforts. We’ve already made great progress in fostering partnerships across University of Michigan programs and departments, other educational institutions (Michigan State University and Wayne State University), and community organizations (Alzheimer’s Association and Lewy Body Dementia Association), but we intend to expand these efforts by providing the latest and most effective educational materials for patients, physicians, and research participants.

There are many opportunities to get involved. For more information, please visit the Support the Center page on our website.
What’s new in RESEARCH

Supporting innovative new research with the 2018–2019 Pilot Project Program

The Center is proud to support innovative, high-impact research into new ideas about the causes and treatment of dementias through our Pilot Project Program. This program offers “kick-starter” research funding to younger investigators at the University of Michigan, Michigan State University, Wayne State University, and Veteran Affairs Ann Arbor Health System so that they can begin testing their ideas. We are pleased to announce the 2018–2019 Pilot Project Awardees:

Male recruitment: Working to close the diversity gap in dementia research

Nationally, men are dramatically underrepresented in dementia research. This is also reflected locally as men comprise only 32% of the research population at the Center. Having a diverse cohort of research participants, reflective of the entire population, is critical in building a strong evidence base for treatment and care. At the Center, we’ve made it a key goal to educate and recruit males into research projects.

This past fall, we took one of the first steps toward this end by participating in the Men’s Health Event hosted by the Men’s Health Foundation in Detroit. We joined over 100 vendors to offer brain health and dementia information to local males. We hope to continue these recruitment efforts by educating about aging research at additional male-focused events in the future.

Additionally, the Center is developing a Community Advisory Board—comprised of male research participants and community members from the Ann Arbor and Detroit communities—which will begin meeting this year. We hope to utilize the expertise and connections of our Community Advisory Board members to reach new men’s health networks, offering education around the importance of male participation in research studies and dispelling longstanding skepticism toward research.

Eunjee Lee, PhD
UNIVERSITY OF MICHIGAN

“Characterization of faster onset of Alzheimer’s disease within mild cognitive impairment patients by brain functional connectivity and genetic variants”

GOAL: Develop advanced statistical models to understand specific brain function and genetic markers that reflect the speed at which mild cognitive impairment converts to Alzheimer’s disease.

Chandra Sripada, PhD
UNIVERSITY OF MICHIGAN

“RNA binding protein sequestration in Non-Amyloid Dementia”

GOAL: Develop new tools to identify toxic RNA interacting proteins in dementia-associated neurological disorders and investigating how those RNA-binding proteins contribute to disease.

Navid Seraji-Bozorgzad, MD
UNIVERSITY OF MICHIGAN

“Cortical Microstructural Changes in African Americans with Alzheimer’s Disease”

GOAL: Use recent developments in MRI to detect the microstructure of the brain, improving early detection of tissue injury and altering the course of disease progression.

Peter Todd, MD, PhD
UNIVERSITY OF MICHIGAN

“Inflammation, social stress, and racial disparities in cognitive aging”

GOAL: Test whether racially patterned social stress (discrimination) partially explains racial disparities in cognitive health through its effects on inflammation.

We are thrilled to support the research into these new ideas, and look forward to seeing how this important research progresses in the coming year.

Rohit Marawar, MD
WAYNE STATE UNIVERSITY

Characterization of faster onset of Alzheimer’s disease within mild cognitive impairment patients by brain functional connectivity and genetic variants”

GOAL: Develop advanced statistical models to understand specific brain function and genetic markers that reflect the speed at which mild cognitive impairment converts to Alzheimer’s disease.

Laura Zahodne, PhD
UNIVERSITY OF MICHIGAN

Center staff at the Men’s Health event with Detroit Lions mascot, Roary
Upcoming research projects target dementia biomarkers

In the last year, the Center received over a dozen grants to support new and growing research projects. Researchers are studying diverse topics, from increased social interaction in the hopes of delaying cognitive decline in seniors, to advancing reliable measures of Alzheimer’s disease via the use of web-based tools. Although the Center’s research is diverse, upcoming research projects place a particular theme at the forefront: biomarkers.

Biomarkers are measurable indicators of disease. Amyloid, tau, and neurodegeneration are the primary biomarkers tied to Alzheimer’s disease. There are various methods by which biomarkers are commonly detected. Examples include blood samples, brain imaging (PET scans, MRI scans, etc.), and cerebrospinal fluid (lumbar puncture). Understanding how the pathological changes of dementia are reflected in these various detection techniques is crucial in helping clinicians offer early and accurate diagnoses. Biomarkers also offer targets for researchers in developing actual interventions in the disease process.

Two upcoming projects at the Center seek to grow the national repository of dementia-related biomarkers.

First, with financial support from the Cure Alzheimer’s Fund, the Center will explore the neurobiological basis of dementia in African Americans. Despite potentially unique risk factors in African Americans, relatively little is known about the biomarkers associated with cognitive impairment. Through this study, we seek to establish disease-defining biomarkers in this understudied population, with an emphasis on vascular changes, quantifying amyloid and tau, and targeted genetic analysis. This information may be crucial in designing new, targeted interventions.

Second, with funding from the Alzheimer’s Association, the Center will be one of three designated sites for a pilot study with the Health and Retirement Study and the Alzheimer’s Disease Neuroimaging Initiative to determine the feasibility of collecting neuroimaging data (structural MRI and amyloid PET scan) from a demographically representative population of older adults. The feasibility of conducting these scans on such a broad group of people has not yet been demonstrated, and will be useful in determining clinical recommendations.

These two projects will roll out in the coming months. We anticipate these projects will help move the knowledge around dementia biomarkers forward, and ultimately benefit the lives of patients and families.

Center faculty named distinguished fellow of American Academy for the Advancement of Science

The Center’s own Roger Albin, MD, was one of 15 researchers at the University of Michigan named a fellow of the American Association for the Advancement of Science (AAAS) on November 27, 2018. This is an honor bestowed upon AAAS members by their peers to honor scientifically or socially distinguished efforts to advance science or its application.

Upon receiving the distinguished award, Albin said, “This is a gratifying honor and due largely to being able to work with many talented colleagues here at the University of Michigan, including several in the Michigan Alzheimer’s Disease Center.”

Albin leads the Research Education Component Core at the Center. In addition to his role at the Center, Albin is also the Anne B. Young Collegiate Professor of Neurology at the University of Michigan Medical School and chief of neuroscience research at the VA Ann Arbor Health System Geriatric Research Education and Clinical Center. He was awarded this great honor for his distinguished contributions to systems and translational neuroscience, particularly for fundamental insights into basal ganglia function and basal ganglia disorders (parkinsonism).

Over 400 new fellows will be honored in February during the 2019 AAAS Annual Meeting in Washington, DC.

Researchers are working to build a blood test to measure dementia biomarkers
BE A LINK | Volunteer for research

We need you! The Center is currently recruiting adults with and without memory changes to participate in our research studies. We have 20 different studies for which you may be eligible.

If you qualify and are interested in participating in a study listed below, please contact Holly Bunker at hlbunker@med.umich.edu or 734-615-5319. Visit the Research page of our website to learn of new research studies seeking volunteers.

Memory Training Studies

Promoting adaptive neuroplasticity in mild cognitive impairment (Merit): Investigating the benefits of two types of treatments for memory impairment — cognitive rehabilitation and electrical brain stimulation. Looking for adults age 50 or older with mild cognitive impairment.

Stimulation to undermine dementia (STUD): Investigating the potential benefits of varying ‘doses’ of non-invasive electrical brain stimulation combined with cognitive rehabilitation. Looking for adults age 55 or older with mild cognitive impairment.

Medication Studies

Dementia with Lewy Bodies Phosphodiesterase Inhibitor Assessment (DELPHIA): Investigating the safety and efficacy of E2027 on cognition in subjects with dementia with Lewy bodies (DLB). Looking for adults age 50-85 with probable DLB.


Imaging and Biomarker Studies

Alzheimer’s Disease Neuroimaging Initiative 3 (ADNI 3): Investigating the relationships among clinical, cognitive, imaging, genetic, and biomarker characteristics of the entire spectrum of Alzheimer’s disease (AD) as it progresses from a preclinical stage to mild symptoms to mild cognitive impairment (MCI) to dementia. Looking for adults age 55-90 with normal cognition, MCI, or mild AD.


Caregiver Studies

Adaptive Coping Engagement with Caregivers of Black Older Adults with Dementia (ACE Project): Investigating caregiver mental health, physical health, and social supports with the aim of developing culturally tailored programming. Looking for adults age 18 or older who are African American/Black caregivers of persons with dementia.

Ocular Imaging in Dementia: Investigating if imaging of the eye can be used to provide investigators new information about diagnosing Alzheimer’s disease (AD) and Frontotemporal dementia (FTD) as well as monitoring the progression of these diseases. Looking for adults age 45-80 who are cognitively normal or have been diagnosed with either AD or FTD.

Risk Evaluation and Education of Alzheimer’s Disease – the Study of Communicating Amyloid Neuroimaging (REVEAL-SCAN): Investigating the best ways to communicate educational information about amyloid imaging brain scans and risk information about the chance of developing Alzheimer’s disease (AD). Looking for cognitively normal adults age 65 to 80 with at least one first-degree relative (i.e., parent or siblings) with AD.

Subjective Cognitive Impairment – A Sign of Incipient Alzheimer’s Disease? Investigating functional and structural brain changes in healthy older adults with and without cognitive complaints. Looking for adults age 60 or older with worrisome memory complaints or a diagnosis of mild cognitive impairment.

Examination of the earliest symptoms and biomarkers of FTLD MAPT carriers: Investigating the earliest clinical features of frontotemporal dementia in an effort to improve early detection of the disease. Looking for adults over 18 with a family member who has frontotemporal dementia.

Lewy Body Dementia Biomarkers: Investigating new brain imaging approaches that investigators hope will identify protein accumulations in the brain of individual patients with Parkinson’s-related dementias. Looking for adults age 55 and older with Parkinson’s disease dementia, dementia with Lewy bodies (DLB), or Alzheimer’s disease (with at least one symptom of DBL).

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Tele-Savvy: An Online Psychoeducation Program for Dementia Family Caregivers: Investigating the psychoeducational program “Tele-Savvy”, an internet-based group education program developed from an in-person program called Savvy Caregiver. Looking for adults age 18 or older who are informal caregivers (family/friends) of persons living with Alzheimer’s disease or another dementia.

Find out more about our research at alzheimers.med.umich.edu.
Pushing dementia discoveries forward

As a result of our ongoing research, the Center published over 20 new research findings in the last year. Faculty affiliated with the Center span from lab bench science to clinical research. As a result, our discoveries and advancements contribute to the true diversity of the dementia field. To briefly summarize a few of our key discoveries:

- Drs. Irving Vega and Scott Counts of Michigan State University discovered that an increase in the protein Ezrin is associated with tau-derived neurodegeneration. (PMID 30101710)
- Director Dr. Henry Paulson and his team discovered important insights about how the protein UBQLN2 functions abnormally in neurodegenerative diseases. (DOI 10.1073/PNAS 1810522115)
- Dr. Annalise Rahman-Filipiak discovered that after further standardization of the diagnosis process, clinicians should weigh informant-reported complaints more heavily than self-reports in diagnosis. (PMID 30124444)
- Dr. Ken Langa discovered that rural adults’ cognitive functioning improves with increased levels of education. (PMID 29246677)
- Dr. Scott Roberts called attention to ethical issues in neurogenetics and helped establish the safety and efficacy of a telephone-based protocol for disclosing genetic susceptibility test results for AD. (PMID 2935614 and 28726810)
- Dr. Peter Lichtenberg confirmed reliability of a scale designed to predict financial decision-making ability when there are changes in cognition. This publication encourages clinician’s use of this scale in assessing financial capacity. (PMID 29077531)

Note: PMID refers to the study’s publication number within the national PubMed database (PubMed.gov).

A new non-pharmacological intervention study for mild cognitive impairment

Neuromodulation is an exciting new tool that may improve thinking (i.e., memory) abilities in those with different types of dementia. Transcranial direct current stimulation (tDCS) is a specific type of neuromodulation that uses weak electric currents to alter activity within a particular brain region or network. tDCS has been shown to be safe and well-tolerated across thousands of sessions with participants of all ages. Initial studies suggest that tDCS may improve cognitive functioning in individuals diagnosed with mild cognitive impairment (MCI) or Alzheimer’s disease (AD). However, very little is known about the most effective ‘dose’ of tDCS so the primary goal of this study is to determine “how much” tDCS is needed for the best possible treatment of MCI.

To answer this question, Dr. Benjamin Hampstead created the Stimulation to Undermine Dementia (STUD) study. In this study, patients with MCI will be randomized to receive five consecutive daily sessions of high-definition (HD) tDCS at different dosages. Stimulation will be focused over the side of the head in order to target brain regions that are affected early in the course of Alzheimer’s disease. The effect of HD-tDCS on thinking abilities will be measured daily, and changes in how the brain is “communicating” will be assessed by comparing functional magnetic resonance imaging (fMRI) before and after the five-day treatment. Patients and their family members will rate their perceived cognitive and functional abilities before and after daily treatments. Each participant will also be asked to complete positron emission tomography (PET) scans so that we can measure if, and how much, Alzheimer’s disease pathology is in the brain.

Through this research, we will address three important questions: (1) Is HD-tDCS well tolerated in this study, as it has been in all previous studies? (2) What dose of HD-tDCS results in the biggest improvements in brain and cognitive functioning? and (3) Does the amount of Alzheimer’s disease pathology in the brain affect the response to tDCS? By answering these questions, our goal is to identify specific treatment parameters so that we can provide an “ideal” treatment for each individual with Alzheimer’s disease.

The STUD study is looking for adults with mild cognitive impairment over the age of 55. If you are interested in participating, please contact Rachael Snyder at rlsnyder@med.umich.edu or 734-936-7360.

Thank you to our generous donors for being Victors for the Center

We envision a day when fear is lost and memories remain

The Center is grateful for the generous donations provided by those who are passionate about dementia research, education, and care. We couldn’t do what we do without this support. Thank you to our donors for your contribution, and for helping us to achieve our mission.

INTERESTED IN MAKING A DONATION? Contact Michelle Davis at 734-763-3555 or bardma@umich.edu
Arijit Bhaumik receives Camille Mrozowski Award for Service Excellence in Research

The Center’s very own Research Administrator, Arijit Bhaumik, BA, CCRP was awarded the 2018 Camille Mrozowski Award for Service Excellence in Research this past September.

Camille Mrozowski’s career in the University of Michigan Medical School Office of Research spanned 27 years. She performed various roles during her years of service, and to each of them Mrozowski brought her personal warmth, integrity, sincerity, and an unwavering commitment to supporting the research mission of the school. She took pride in her work, and always went above and beyond in helping her faculty, coworkers, and the diverse customers of the Office of Research. Mrozowski made everyone she interacted with feel important and appreciated.

Mrozowski passed away prematurely in 2016, and her colleagues in the Office of Research created this award to honor the memory of their beloved coworker. The award is intended to recognize research support staff who bring a personal touch to their interactions, exhibit a positive attitude, demonstrate professionalism and perseverance, and inspire coworkers.

This award recognizes Bhaumik’s passion, professionalism, tireless commitment, and extraordinary care for both researchers and their patients. As the Research Administrator of the Center, Bhaumik supports countless research activities, from managing research projects to training study coordinators to balancing complex research budgets. Bhaumik is an excellent communicator, emphasizing creative strategies for multicultural and cross-generational understanding of research within the Center. He has managed neurodegenerative clinical trials and longitudinal studies at the Center for more than 12 years.

The Office of Research celebrated Bhaumik and remembered Mrozowski at an award reception on September 21.

Center thanks record high number of research participants, donors, and partners at luncheon

In November, we welcomed nearly 300 research participants, donors, and community partners to Ann Arbor for our annual Appreciation Luncheon. The luncheon is held every year to recognize and appreciate the commitment of our many partners. Our guests enjoyed live music from the Community High School Jazz Band, a presentation on the latest developments at the Center, and a Q&A panel featuring experts from a variety of disciplines. Presentations by Laura Rice-Oeschger, LMSW on the new THRIVE program for caregivers and Kenneth Langa, MD, PhD on recent dementia prevention research were also featured.

New this year, we presented Champion Awards to three community partners and donors for their incredible dedication and service to the Center. Reverend Dr. Edward Duckworth was recognized for his role in championing African American involvement in Center research. In addition, Linda Day and Cindy Marshall were jointly recognized for their fundraising efforts from both their local Burton — and now statewide — Fraternal Order of Eagles.

We’re grateful for the support and efforts of our many partners. Truly, every one of our research participants, donors, and community partners are champions in our common pursuit of an intervention to the dementias.

If you’d like to review the presentations from the 2018 Appreciation Luncheon, they are available on our website.
A look into the Michigan Brain Bank

The Michigan Brain Bank collects, stores, and distributes brain tissue to the scientific community to support research into neurological diseases, including Alzheimer’s disease and related dementias, Parkinson’s disease, Huntington’s disease, ALS, and other less common neurogenetic disorders. Examining brain tissue helps researchers better understand the causes of these diseases as they seek to develop potential treatments and preventive strategies, and improve diagnostic methods.

This important resource is only possible because of the generosity of individuals who choose to donate their brains to science. At the University of Michigan, the Brain Bank receives donations from donors who have been participants in affiliated clinical research studies, such as those at the Center. Individuals and their families who are interested in brain donation discuss and consent to the process well in advance of the time of death to ensure that all preparations align with the wishes of the patient and their family, without added burden or cost during a difficult time.

Matthew Perkins, BS coordinates all activities of the Michigan Brain Bank, from performing autopsies to distributing tissue to researchers. When a donor passes away, Perkins is the person the family calls—24 hours a day, 7 days a week, 365 days a year. He arranges logistics—speaking with families, hospice nurses, funeral homes, pathologists, and others—conducts the autopsies (or coordinates out-of-state autopsies when necessary), and facilitates the process through which pathologists and students at the University of Michigan analyze the donated brain. All families receive a copy of the autopsy report, which can prove helpful in documenting family health history information.

Perkins also coordinates the distribution of brain tissue to researchers both at the University of Michigan and across the country. When a brain is donated to the Michigan Brain Bank, half of it is frozen for long-term storage and the other half is preserved with a fixative and then embedded in a paraffin wax block. Researchers can request small sections of tissue. Because a typical section is just 5 microns thick, one brain could potentially contribute to hundreds of research studies. While his interest in neurology set him on his path to his current role at the Michigan Brain Bank, Perkins says his favorite part of the job is working with people: “It’s very rewarding to be able to give back to these patients and their families, who have gone through a lot. When we do these autopsies and accept these donations, we’re really fulfilling the wishes of the loved ones. They’ve decided they want to make a contribution to research and we’re just here to make sure that they can.” Dementia can only be diagnosed through postmortem autopsy, so brain donation can also serve an important role in providing closure for the family when they receive the final autopsy report. But ultimately, Perkins says, the choice to donate is often driven by a desire to support the research. “Most of the time, the attitude is: I’ve suffered and I don’t want someone else to have to suffer. So if I can do something to prevent that…. They’re often thinking about others when they make this decision.”

Learn more about the Michigan Brain Bank at brainbank.umich.edu. If you or a family member is interested in participating in brain donation, please contact Matthew Perkins, Michigan Brain Bank Coordinator, at perkmd@med.umich.edu or 734-647-7648.

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

Brain donation is one of the greatest gifts to further dementia research. Our staff work alongside families to ensure wishes are met, loved ones are thoughtfully cared for, 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.
How is Lewy body dementia different from other dementias?

Lewy body dementia (LBD) is the second most common form of progressive dementia. An estimated 1.4 million Americans in the United States have LBD. The symptoms of LBD overlap with other well-known diseases, like Alzheimer’s and Parkinson’s diseases. This leads to misdiagnoses, with only 30 to 50% of LBD cases being accurately diagnosed.

Ann Arborite Tamara Real faced this very issue when her husband Carl Rinne experienced symptoms that left many doctors without answers. When they finally received an LBD diagnosis here at the University of Michigan, Real resolved that others should not face the same uncertainty about a disease that often goes unrecognized or misdiagnosed. To honor her husband and to continue this mission, Real established the Rinne Lewy Body Dementia Initiative here at the Center.

What makes LBD different?

“Lewy bodies” are abnormal clumps of the protein “alpha-synuclein” that build up in the brain. These deposits are the biological process that sets apart LBD from other dementias. Lewy bodies are found inside brain cells. They are also found in Parkinson’s disease (PD), but the number of cells containing Lewy bodies in PD is far lower than in LBD. Researchers still don’t know exactly how, but Lewy bodies impair the function and health of brain cells. In time, they lead to loss of the cells (“degeneration”).

There are no tests, like brain imaging or other technology, which can detect Lewy bodies in living people. We can only see Lewy bodies by looking at brain tissue under a microscope. Researchers are actively looking for biomarkers (biological measurements) that can distinguish LBD from other dementias. Examples include blood and spinal fluid.

For now, however, we rely heavily on clinical clues. Alzheimer’s disease often starts with decline in memory. In comparison, people with LBD often have a wide range of other symptoms, which include:

- Visual hallucinations
- Significant day-to-day fluctuations in abilities or alertness
- Stiffness and slowness of movement (parkinsonism)
- Acting out dreams (REM sleep behavior disorder)

By themselves, none of these symptoms is sufficient to make the diagnosis, and not everyone with LBD develops all these symptoms. Visual hallucinations and parkinsonism, for example, are well recognized hallmark features of LBD. However, they are not always the first symptoms.

As LBD progresses, the intensity of symptoms may change over time, improving or worsening. What a person with LBD experiences this month may not happen next month. This uncertainty and fluctuation can be stressful for everyone affected by LBD.

Accurate diagnosis of LBD is critical.

Putting a name to this disease helps people with LBD and their families. They move beyond what can be an emotionally draining search for a diagnosis. Accurate and early diagnosis of LBD allows individuals and families to understand current symptoms and plan for future issues that might arise. Such knowledge can be empowering.

Making the right diagnosis also ensures that potentially helpful medications are offered. For example, medications developed originally for Alzheimer’s disease may help cognitive symptoms in LBD. The stiffness and slowness of LBD may improve with medications typically used for PD.

Equally important, medications that could be dangerous are avoided. Many antipsychotic medications used to treat behavioral symptoms can cause problems in LBD. This includes worsening of stiffness and slowness.

A diagnosis of LBD is made after a thorough evaluation. This includes a review of symptoms and current medications, a neurological exam, brain imaging, and blood tests. Some of these tests rule out other medical conditions that, if not properly treated, can mimic the signs of dementia. (Examples include vitamin deficiencies or thyroid disease.)

Additional cognitive testing, spinal fluid analysis, brain wave study (EEG), and/or a sleep study may provide further clues to diagnosis. Sometimes it is necessary to monitor clinical change over time to be more sure of the diagnosis.

The Rinne Lewy Body Dementia Initiative is committed to supporting care partners and people with an early LBD diagnosis, educating health care workers, and building public awareness of LBD in Michigan.

Lewy Body Dementia Support Groups

Monthly support groups are held at the following locations for those with an early diagnosis of LBD and for caregivers / family members of those with LBD.

**ANN ARBOR**
2nd Tuesday of each month, 2:00-3:30 pm
Huron Woods Towsley Health Building
5361 McAuley Dr.
Ann Arbor, MI 48106

**BRIGHTON**
2nd Wednesday of each month, 6:00-7:30 pm
Caretel Inns of Brighton
1014 E. Grand River Ave.
Brighton, MI 48116

**SOUTHFIELD**
4th Thursday of each month, 2:00-3:30 pm
Alzheimer’s Association (Mars Building)
25200 Telegraph Rd.
Southfield, MI 48033

For more information on LBD, visit our website or the lbda.org. If you would like to learn more about local support groups and LBD educational opportunities please contact Renee Gadwa at rgadwa@med.umich.edu. If you would like to subscribe to the monthly LBD e-newsletter, please contact Erin Fox at eefox@med.umich.edu.
Leading caregiver wellness with ‘Mindfulness-based Dementia Care’ course

As the prevalence of dementia continues to grow, so does the prevalence of family caregivers. Family caregivers experience many unique challenges including lack of pay, the burden of providing care while oftentimes still working themselves, the emotional burden brought on by changes in family relationship dynamics, and more. In fact, according to the Alzheimer’s Association Facts & Figures Report (2014), 61% of dementia caregivers suffer from high or very high emotional stress and 40% have symptoms of depression.

The Center’s Wellness Initiative specifically addresses the challenges faced by family caregivers of adults living with memory loss. The Initiative offers a variety of stress-resilience programs to prepare caregivers for the ever-changing responsibilities of caregiving. Uniquely, the Center’s Wellness Initiative facilitates an eight-week course called Mindfulness-based Dementia Care that is the only program of its kind for the dementia caregiver.

Mindfulness-based Dementia Care (MBDC) was created by Marguerite Manteau-Rao, LCSW, a personal friend and colleague of the Wellness Initiative’s, Laura Rice-Oeschger, LMSW. In 2014, the Center became the third location in the country to offer the MBDC course, and since has taken a lead role in not only facilitating but also growing the program both domestically and abroad through partnerships with the Presence Care Project. For example, in 2017, the Center became the first host location to train new facilitators in the MBDC program; this training included seven participants across three countries.

MBDC builds upon the practice of mindfulness, applying it specifically to the challenges and stresses faced in dementia care. While not all stress is inherently bad, there are stressors common in dementia caregiving that may become mentally draining, physically damaging, and emotionally overwhelming. Mindfulness offers invaluable resources and coping practices that can improve well-being and quality of life for both the caregiver themselves and the person in their care. Studies even suggest that mindfulness may lower anxiety, stress, depression, and caregiver burden, while increasing overall mental health, self-compassion, and social support.

Over the past four years, 100 family caregivers have participated in MBDC at the Center. A previous participant in the course shared the profound impact it’s had on their caregiving experience: “I feel this knowledge and experience is really the only way to successfully travel through this journey of caregiving.”

One of the biggest takeaways of the course is building caregiver confidence. One participant shared that “The transformation in my husband and in our relationship takes my breath away. He clearly feels safer. We are enjoying more shared experiences. This class feels like a gift that enriches both our lives and builds relationship no matter how the future unfolds.”

Rice-Oeschger summarizes the course: “It’s amazing to be able to hear of relationships transforming because of the wisdom in this program. Because of MBDC, caregivers are able to be more in tune with themselves, allowing them to see more clearly their partner’s needs. They become confident in moving through challenges because they can see the wisest choice. Not only do these skills minimize harm, they also increase compassion.”

In addition to MBDC, the Center’s Wellness Initiative also offers a monthly stress resilience program, Catching Your Breath, and a twice-a-year retreat, Caregiver Wellness Day. Wellness Initiative programs are possible because of generous donors to the Michigan Alzheimer’s Disease Center.

What is mindfulness?

Mindfulness is a skill and practice that involves training the brain to pay attention to the present moment, with nonjudgmental awareness, acceptance, openness, and curiosity of ‘what is.’

Additional resources for caregivers:

- Caring for a Loved One with Dementia by Marguerite Manteau-Rao, LCSW (2016)

More information and registration for Wellness Initiative programs is available on our website. If you would like to subscribe to the monthly Wellness Initiative e-newsletter, please contact Erin Fox at eefox@med.umich.edu
Announcing launch of “Dementia for Scientists” online curriculum

The Center is pleased to announce the release of its “Dementia for Scientists” curriculum. The curriculum is now available to view on YouTube. The goal of this curriculum is to provide a broad and current introduction to important aspects of dementias and dementia-related research. The target audience is junior investigators.

Why did we create this curriculum? Dementia research is highly diverse in content, ranging from basic biophysics to social science. While investigators entering the field from diverse backgrounds are well-trained in their own discipline, they may lack broader knowledge of the many aspects of dementia and dementia research that are important to understand key issues in the field. This curriculum provides a relatively sophisticated introduction to critical aspects of dementias across the broad sweep of the field. Our goal is to enhance the ability of junior investigators to read and understand relevant literature outside their own disciplines.

The curriculum consists of seven modules, each of which addresses an important area in contemporary dementia research. The modules begin with basic definitional material (Dementia Definition and Evaluation) and proceed through biology of dementias (Dementia Pathology & Pathogenesis; Dementia Genetics), clinical research (Dementia Imaging; Therapy Development in Dementias), and important policy and social science aspects of dementias (Health Services and Policy Dementia Research; Research Performance in Ethnically Diverse Populations).

We hope you find the curriculum valuable. This is our initial effort and we welcome all comments, criticisms, and suggestions. Please send all feedback to Erin Fox at eefox@med.umich.edu.

To access the curriculum, search for the Michigan Alzheimer’s Disease Center on YouTube.