Feedback Program Expansion Enhances Communication with UM-MAP Research Participants

One of our missions as a federally funded research center is to maintain a group of research participants whose memory and thinking abilities we study over time. This cohort, our University of Michigan Memory and Aging Project (UM-MAP), invites participants to take part in annual evaluations including questionnaires, interviews, thinking tests, and other procedures like a blood sample or a brain scan. After these procedures are complete, our expert team reviews them to determine if there is any evidence of memory or thinking problems. These results are studied over time, and the data are used by researchers nationwide to understand and improve treatment options for memory and cognition.

Because our research procedures are so in-depth – necessary to fully understand the innerworkings of thinking and memory that could lead to new discoveries! – our center is ideally positioned to identify cognitive changes in our participants throughout their time in our study. Annalise Rahman-Filipiak, Ph.D., Assistant Professor in the Department of Psychiatry at U-M Medical School and one of our investigators, found in her work that nearly 96 percent of UM-MAP participants want to receive their cognitive test results and any research diagnosis made by our research team.

We are pleased to share that all participants enrolled into UM-MAP can now receive results from their annual assessment and learn their “research diagnosis” (that is, a general diagnosis that classifies participants as cognitively normal, mild cognitive impairment, or dementia). We’ve also enhanced the process to include families in feedback sessions, provide visual materials to better explain changes, and share improved resource packets. Providing this new service is a big step forward in our capabilities as a center.

What moved us to begin this new program?

In addition to our participants requesting their results, access to specialty neurological care services is limited and many of our research participants do not have access or may wait months to see a specialist. We hope having this information can help our participants feel more prepared to talk with their doctors about their results, change their health behaviors (such as diet and exercise), engage in advanced planning, and select future research studies that are the right fit for them. Although research evaluations should never take the place of clinical care, our center is well-equipped to provide individuals with health information that they may not otherwise receive.

When asked about this project, Dr. Rahman-Filipiak stated,

“A huge part of the decision to participate in research is trust. Trust is built through two-way communication and transparency, and we feel that returning personal research results achieves both. We are proud of the rapid growth of our feedback program over the past five years. We are now able to make this feedback accessible to all our participants who dedicate so much time and energy to our work.”

What is coming next for this new and important program?

Dr. Rahman-Filipiak recently launched a new research project called Outcomes Following Feedback on Research Results (or OFFeR). Through this program, we will ask our UM-MAP participants about their feedback experience, including how well they understood their results and how they are using the information they learned. Providing this new service is a big step forward in our capabilities as a center.
Note from the Director

Greetings from Ann Arbor, where I’m finally wearing my Michigan ADRC knit cap! Whenever I go outdoors these days, I am happy to advertise our mission as a center.

While it may be cold outside, I’m still basking in the warm glow of our Appreciation Luncheon held a few weeks ago in Ann Arbor. More than 200 people turned out for our first such event in – wait for it - three years! It was a momentous celebration, and the joy and energy in the room were nearly palpable. This event gave us a chance to thank YOU for making our research activities possible and to give our research participants, their families, and our donors an opportunity to meet all our staff. Ten years ago, our luncheons were much smaller, because, frankly, our center was much smaller. But now, thanks to the commitment of so many across our state, we are engaged in dozens of research projects and evaluate hundreds of people annually. The only way we will find answers to Alzheimer’s disease, Lewy Body dementia, vascular dementia and frontotemporal dementia is by studying people. People make this possible. So, thank you from the bottom of my heart.

That luncheon also gave us a chance to honor one of my personal heroes in the center, Dr. Annalise Rahman-Filipiak, one of our new class of junior investigators (see page 4 for the full announcement). His research focuses on developing and applying data-driven approaches to evaluate a wide variety of environmental factors in aging-related diseases, including Alzheimer’s disease. Dr. Wang’s research focuses on common pollutants, including metals such as lead, mercury, arsenic, cadmium, selenium, and manganese.

Could Environmental Pollutants Play a Role in Alzheimer’s Disease?

As our center has changed over the years, we’ve come to realize we must do a better job of giving back to the communities who help us carry out the research we do. Toward that goal, I am proud to say that we have developed an innovative feedback program that promises to be a model for the nation. One of our center’s young lights, Dr. Annalise Rahman-Filipiak, has developed this feedback program. She is already working with centers across the country to implement standardized approaches to offer results to our research participants. In many cases, learning information about one’s own disease can help promote lifestyle changes that offer great benefit. I believe the impact of this program is going to be massive and, a few years from now, may well be one of the key reasons our center is viewed as a leader across the country.

Let me conclude by wishing you well as we enter the holiday season. May it be filled with peace, joy, and plenty of good food!
Welcoming our 2022-2024 Class of Junior Investigator Mentees

Mentoring the next generation of dementia and aging researchers is key to our mission as a center. Each year, we are excited to bring in our next class of junior investigators entering the field of dementia research. Our program provides these young investigators with a broad education about contemporary dementia research and mentoring by experienced investigators in developing competitive grant applications.

This year we welcome the following researchers:

**Kelly DuBois, Ph.D.**
Dr. Kelly DuBois is a postdoctoral fellow in the department of translational neuroscience at MSU. She completed her B.S. in biotechnology from Calvin University, after which she completed a Ph.D. in biomedical science at the University of California, San Francisco. She then completed a Postdoctoral Fellowship in the department of pathology at Cambridge University in the UK, where she studied molecular parasitology, before joining our partners at MSU in 2021. Dr. DuBois' research focuses on the development of blood-based assays for the detection of Alzheimer’s disease and other tauopathies. She hopes to better understand the normal function of the tau protein and how pathological forms of tau may disrupt its normal function, leading to disease.

**Katherine Kero, Ph.D., R.N.**
Dr. Katherine Kero is a postdoctoral research fellow with the ELECTRA study in Dr. Voyko Kavcic’s lab at WSU’s Institute of Gerontology. In her postdoctoral research role, she partners with experts from diverse disciplinary backgrounds to examine the physical, psychological, and social determinants of cognitive health and behavior with a focus on functional abilities and quality of life outcomes. Dr. Kero’s research interests include health promotion, disease prevention, and health equity for older adults and caregivers. As a mentee, she will evaluate the effects of a cognitive exercise program on cognitive performance measured by EEG and behavioral assessments.

**Alexandru Iordan, Ph.D.**
Dr. Alexandru Iordan is an Assistant Research Scientist in the U-M department of psychology. Dr. Iordan completed his Ph.D. in neuroscience at the University of Illinois and joined U-M in 2016 as a Postdoctoral Fellow. Dr. Iordan’s research aims to clarify the neural mechanisms underlying cognitive plasticity in healthy and pathological aging by combining multimodal imaging with training and neuromodulation. His interests converge toward developing and applying non-pharmacological treatments with measurable neurobiological outcomes for Alzheimer’s disease and related dementias.

**Pilar Rivero-Rios, Ph.D.**
Dr. Pilar Rivero-Rios earned her master’s and doctorate degrees from the University of Granada, Spain. While a graduate student, she investigated how pathogenic mutations in LRRK2, the main genetic determinant of Parkinson’s disease, alter the movement of proteins throughout a cell. Now, as a postdoctoral researcher in the U-M Life Sciences Institute, Dr. Rivero-Rios studies how altered vesicular trafficking in neurons lead to synaptic loss and Alzheimer’s disease.

**Tongtong Li, Ph.D.**
Dr. Tongtong Li earned her Ph.D. in electrical and computer engineering in 2000 from Auburn University, and her Ph.D. in mathematics in 1995 from Sun Yat-Sen University. She is professor in MSU’s department of electrical and computer engineering. Dr. Li’s research interests are in brain network analysis using communication theory, with applications to Alzheimer’s disease. Using tools in communication theory, artificial intelligence and machine learning, Dr. Li studies non-invasive biomarker development for the early diagnosis and prediction of Alzheimer’s disease and analyzes the effect of different interventions on dementia.

**Xin Wang, Ph.D., M.P.H.**
Dr. Xin Wang is a Research Investigator in the department of epidemiology at the University of Michigan School of Public Health. Dr. Wang received his M.P.H. and Ph.D. in epidemiologic science from the University of Michigan. Read more about Dr. Wang’s research on page 3.

**Want to learn more about previous classes of mentees?**
Visit alzheimers.med.umich.edu/for-professionals and click the REC Mentorship tab.
Creating Purpose for Individuals Living with Mild Cognitive Impairment

John Piette, Ph.D., U-M professor of internal medicine and health behavior and health education studies depression and suicide, and their root causes – including social isolation and loneliness – in underserved populations in Latin America. When he visited nursing homes here in the United States, he also found social isolation and loneliness. Although these facilities offered regular activities, they did not provide a substitute to the feeling of being needed. Drawing connections to his previous work, he worked to create a meaningful opportunity for both groups with a new program called “Seniors Promoting English Acquisition Knowledge (SPEAK)”!

Dr. Piette knew that non-English-speaking individuals were uncomfortable attempting to speak English but were hoped to learn to speak it fluently because it would lead to more economic opportunities. To build the program, he worked with employers that regularly employed non-English speaking employees including Molly Maids, McDonalds, and hotel chains. He also found that many young faculty at U-M felt socially isolated on campus because they had trouble communicating with others outside their office. They hoped that speaking English would help in integrating well into campus life.

Connecting with Dr. Benjamin Hampstead and Dr. Scott Roberts of our center faculty, Dr. Piette learned more about cognitive impairment research, and utilized our center’s research registry to recruit individuals with mild cognitive impairment (MCI) to join his program. His goal was to connect older adults with MCI to English Language Learners (ELLs) to hold regular conversations via Zoom.

Although data analysis is still underway, the researchers have seen positive results. The frequency and complexity of requests for our data have increased tremendously in recent years. This is an exciting step as a center because we are using participant data to bring innovative research questions and new research to the national network.

As our work has expanded and developed, investigators from across our institutions suggested we invest in a talented statistician to meet the growing demand of digesting our complex data. This summer, to support our cutting-edge research, we hired a full-time statistician. We are excited to welcome Subhamoy Pal, Ph.D., to our team.

Dr. Pal graduated with his doctorate in applied statistics from Bowling Green State University in 2021, and already in his short time on our team has been involved in analyses that supported senior investigator’s research initiatives and new grant submissions. Given our center’s focus on mentoring junior investigators, we know Dr. Pal will continue to support the work of leading junior researchers for years to come.

We are at the cusp of our growth in Data Core and know our team will continue to grow in the next five years and beyond.

What’s New in the Data Management and Statistical Core?

Alzheimer’s Disease Research Centers (ADRCs) work together across the United States to investigate Alzheimer’s disease and related dementias from many angles, and treat dementia. To meet this charge, ADRCs generate data from multiple domains, including neuropsychiatric testing, neuroimaging, and biomarker assessments. All of these data need rigorous quantitative analyses conducted by dedicated and highly skilled analysts, so that the findings can be shared with the community and move Alzheimer’s disease research and treatments forward. This is the role and charge of our Data Management and Statistical Core.

Over the past seven years, as our center grew and incorporated new cores and a larger longitudinal cohort, the breadth of our data has grown too. Each time a research participant comes for a visit, the data from their visit is verified and uploaded to a national database. With the size of our longitudinal cohort growing (497 active participants!), this process has become robust. To tackle this challenge, we recently introduced advanced database engineering and analytic methods. These new systems offer improved private communication with our participants, enhanced data storage security (it is HIPAA compliant), and greater reproducibility and accessibility for our researchers.

Our staff has been tremendously agile throughout this growth, and we are grateful for their enthusiasm in implementing these new technologies. We are fortunate to have such a depth of knowledge and breadth of skills across our team.

Accompanying the expansion of our database is the growing number of investigators across our three institutions that request access to our data to support their studies. The frequency and complexity of requests for our data have increased tremendously in recent years. This is an exciting step as a center because we are using participant data to bring innovative research questions and new research to the national network.
New Institution, Same Collaborations with the Michigan ADRC

After a nine-year tenure with the University of Michigan, Amanda Leggett, Ph.D., makes a move to Wayne State University to continue her research and advance her outreach to the community.

Amanda Leggett, Ph.D., began her career at the U-M where she spent nine years as a Postdoctoral Research Fellow and Research Assistant Professor in the division of geriatric psychiatry. Her research focuses on the development of a taxonomy of dementia caregiving care management work. Having recently received a new R01 award from the National Institute on Aging to understand caregiver networks and their associations with care outcomes. She hopes this study will ultimately improve the assessment of caregiving processes by focusing on understanding the connections between interpersonal dynamics within families and their association with patient health and well-being outcomes.

Though her institution has changed, Dr. Leggett will continue to work closely with our center as a member of our Leaders Initiative. She will maintain connection with Drs. Hampstead and Hedebrink as a key member of our Clinical Core and continue to collaborate with our research participants and staff to advance her research.

We are excited to watch Dr. Leggett’s career expand in her new role and are thrilled that her work with her will continue at her new institution.

An Exciting Time for Lewy Body Diseases Research

The term “Lewy body diseases” refers to a major family of neurodegenerative diseases including Parkinson’s disease and Lewy body dementia. The hallmark Lewy body is an abnormality found in nerve cells of affected individuals. In the early 1990s, Lewy bodies were discovered to be composed of a protein called alpha-synuclein. It is widely believed that abnormalities in the production, removal, or function of alpha-synuclein cause nerve cell death in Parkinson’s disease and Lewy body dementia.

A wide spectrum of research at U-M focuses on Lewy body diseases. Some work aims to understand how abnormalities of alpha-synuclein production, removal, or function cause nerve cell death. Several U-M laboratories, including center director Dr. Henry Paulson’s lab, are trying to understand the basic cellular processes that affect alpha-synuclein processing in cells within the brain.

Ongoing clinical research aims to modify the progression of cognitive impairment in Lewy body diseases through several available interventions. Dr. Vikas Kotagal is evaluating a commonly used anti-depressant drug as a potential treatment for cognitive decline in Lewy body diseases. Dr. Benjamin Hampstead is evaluating the use of transcranial electrical stimulation (tES) as a potential treatment for cognitive challenges in individuals living with LBD or Parkinson’s disease dementia.

Supported by a generous grant from the Farmer Family Foundation, a group of U-M investigators in the departments of neurology and radiology are exploring if alternative metabolic approaches might modify the progression of cognitive decline in Parkinson’s disease.

A major focus in Lewy body dementia research nationally is on the improvement of education of health care professionals about the disease and how to improve quality of life in these individuals. We are thrilled to contribute to this research by participating in a multi-site study led by Dr. Melissa Armstrong (University of Florida) that seeks to understand what changes might predict end-of-life in people living with LBD, in order to help patients, their families and health care professionals know what to expect in the later stages of the disease.

This is an exciting time for research on Lewy body diseases as we improve our understanding of Parkinson’s disease and Lewy body dementia and identify promising targets for therapies. A limitation in our efforts to expand this research is a shortage of research volunteers. We strongly encourage individuals with Parkinson’s disease or Lewy body dementia to consider participating in research. You can find more about these opportunities on our website at alzheimers.med.umich.edu or the U-M Udall Center for Excellence for Parkinson’s Disease Research website at udallpd.umich.edu.

An Exciting Time for Lewy Body Diseases Research

Registration is not required for our in-person support groups, but first-time attendees and anyone with questions, please reach out to Renee Gadwa at rgadwa@med.umich.edu or 734-764-5137. Visit alzheimers.med.umich.edu/ldb-registration to register for our virtual support groups.

Virtual Afternoon Support Group
Second Tuesday of the Month
2 – 3 p.m. for caregivers
3 – 4 p.m. for those living with LBD

Virtual Evening Support Group
Second Tuesday of the Month
6 – 7 p.m. for caregivers

Boyne City Support Group
Second Tuesday of the Month
2 – 3 p.m. combined group for both caregivers and those living with LBD

Sommerset Pointe Yacht Club and Marina
00970 Marina Drive, Boyne City, MI 49712

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“I got into research to make a difference in the community. I always wanted that to be my priority over publishing papers or writing grants. I am excited that my new role allows me to have a foot both in an academic department and in a multidisciplinary institute so that I can be involved in the community.”

Dr. Leggett will also work alongside Dr. Lichtenberg on two upcoming initiatives. The first is a caregiving toolkit in partnership with the Michigan Health & Hospital Association Keystone Center and Henry Ford Hospital – work funded by the Michigan Health Endowment Fund. She will also represent the IoG at the statewide Michigan Dementia Coalition – an important initiative to bring together stakeholders across disciplines to guide dementia work for our state.

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the Michigan ADRC

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In her new role, Dr. Leggett is excited about teaching and hopes to bring her love of working with older adults to new graduate and undergraduate students.

She is also excited about working closely with community members and organizations in this new role. Dr. Leggett will work with the IoG Director and our center’s REC co-lead, Dr. Peter Lichtenberg, in his efforts to extend outreach to Detroit.

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A look back over a decade of supporting caregivers in their wellbeing

Celebrating 10 Years of our Wellness Initiative

Ten years ago in May, we began our caregiver wellness programs. After many years of working closely with adults with dementia at the Turner Senior Wellness Center, Wellness Initiative Managing Director, Laura Rice-Oeschger, LMSW, made a significant and personally meaningful shift in 2012: creating wellbeing programs for care partners within our center. With generous donor support, and a welcoming partnership with the Matthaei Botanical Gardens, the Wellness Initiative began to take root as an uplifting and healing space for exhausted caregivers.

Building the legacy of Catching Your Breath

The Wellness Initiative began as a space for caregivers to gather for training and community in our monthly program, Catching Your Breath. This is our skill-development, mindfulness-informed program for family caregivers. It offers self-care practices that focus on developing stress resiliency over time. For eight years, Matthaei offered the backdrop of nature that became synonymous with our Catching Your Breath program, and our twice annual caregiver wellness day retreats. It offered a serene and calming setting for caregivers to exhale and find connection with each other and with nature.

Expanding across the state

As the years went on, the need to expand our programs became clear. We could only reach those caregivers within our region, and even then, so many experienced barriers to attending an in-person or time-specific program. One significant step toward expansion was our work to create a collaborative state network. In 2017, in partnership with Michigan State University – Extension, WSU Institute of Gerontology, and a grant provided by the Michigan Health Endowment Fund, we established the THRIVE Network to manualize and share the Catching Your Breath model with other sites across the state.

This network also laid the foundation for a web-based collaborative that would make access to programs easier for caregivers to navigate.

The COVID-19 pandemic brought long-time aspirations to life

The COVID-19 pandemic brought a new set of challenges. Though caregivers needed support and connection more than ever, the option for in-person programming was eliminated. To continue to meet their needs, our team pivoted, enacting what had long been an aspiration of Laura Rice-Oeschger, LMSW: to meet program participants, new and regular, online.

We hoped to meet even more caregivers with our programs due to the flexibility and far-reaching nature of technology but had concerns that it might limit our ability to connect or change the feel of the program. We were encouraged to discover that connecting online was not only accessible, but also sustainable, and offered a deeply connecting experience for participants. This new format presents its own unique benefits outside of our in-person programs and has become far-reaching. We are excited to reach new caregivers as far away as Michigan’s Upper Peninsula and the country’s east coast in such a short time by moving virtually.

Building the legacy of Catching Your Breath

Finally, as we wrap up our tenth year of programming, we are excited to unveil our new CALM Connections virtual wellness platform. CALM, which stands for Caregiving and Living in the Moment, brings together the Catching Your Breath foundation into a self-paced curriculum, offering in-depth learning modules, practices, and resources. The topics emphasized in CALM Connections were collected over our ten years of learning and working alongside care partners through their many years of experience in caregiving. CALM also offers the key component of virtual peer connection that is necessary for caregivers coping with stress, loss, and change while maintaining their own health and wellbeing. It is just the beginning of what we hope will be a living and dynamic resource to support caregivers for years to come.

Please visit us and share our resources and activities with caregivers you know, near and far. Visit calmconnections.med.umich.edu to learn more.

Thank you for ten exciting and supportive years of our Wellness Initiative!

Want to learn more about the Wellness Initiative?

Visit alzheimers.med.umich.edu/wellness-initiative to sign up.

Wellness Initiative Programs

Caregiver Programs:
- Catching Your Breath
- Monthly, skill-development program
- CALM Conversations
- Quarterly, theme-based facilitated discussion
- Happy Enough Hour
- Monthly social hour for regular program participants
- Living Grief
- Annual, six-month program, new session to begin in May 2023
- Mindfulness-based Dementia Care
- Twice annual, eight-week program; new sessions begin in January and April 2023

Programs for Persons Living with Dementia:
- Mitten Minds Education Series
- Twice annual, six-week educational program providing important information to those newly diagnosed with dementia, providing a space for questions to be answered and to connect with resources and support services available
- Mitten Minds Support Group
- Monthly support group for persons with a recent dementia diagnosis

Programs open to anyone:
- Have a Seat
- Weekly drop-in mindfulness meditation practice session

Visit alzheimers.med.umich.edu/wellness-initiative

Laura Rice-Oeschger, LMSW
Theresa Gierzynski, LMSW
Ashley Miller, M.P.H.

Supporting new programs, audiences, and staff

As we have reached new caregivers near and far, we’ve also added new programs and staff to expand the Wellness Initiative. Three programs in the making over the past few years include our Living Grief program, Happy Enough Hour, and Mitten Minds Education Series and support group. The latter two programs expand our Wellness Initiative to reach persons living with dementia.

We were also eager to bring in Theresa Gierzynski, LMSW and Ashley Miller, MPH to support our growing programs. Theresa supports our new Living Grief program and Happy Enough Hour, and Ashley built and supports our programs for persons living with dementia.

Bringing together 10 years of wellness programs online

Enough Hour
Living in the Moment
Happy Enough Hour
Catching Your Breath
Mitten Minds Support Group
Mitten Minds Education Series
Have a Seat
Catching Your Breath
Monthly, skill-development program
CALM Conversations
Quarterly, theme-based facilitated discussion
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Visit calmconnections.med.umich.edu to learn more.
Save the Date for our Speaker Series!

Join us virtually in the new year! Our monthly Speaker Series brings our experts to the public to share about a variety of dementia and aging-related topics.

“What’s New in Alzheimer’s Disease Clinical Trials”
Tuesday, January 24 at 3 p.m.
Presented by Judy Heidebrink, M.D., M.S., a practicing Michigan ADRC neurologist with vast experience leading clinical trials testing new treatments for Alzheimer’s disease
Register: michmed.org/yVR98

“Blood Pressure Control: Current Trends and Opportunities in the Black Community”
Wednesday, February 22 at 12 p.m.
Presented by Lenette Jones, Ph.D., ACNS-BC, R.N., a behavioral nurse scientist studying how to improve self-management of blood pressure among African Americans
Register: michmed.org/ZY2QK

“Race, Ethnicity, Depressive Symptoms, and the Alzheimer’s Disease and Related Dementia Spousal Caregiver”
Wednesday, March 22, 2023 at 12 p.m.
Presented by Florence Johnson, R.N., a doctoral student studying the relationship between community support use and mental health in Black family caregivers
Register: michmed.org/xXZB4

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.

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

Visit our website at alzheimers.med.umich.edu

Support
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