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# Mesulam Center

FALL 2024

A News Publication of the  
Mesulam Center for Cognitive Neurology  
and Alzheimer's Disease



**Redefining Aging:  
25 Years of  
SuperAging at  
Northwestern** PAGE 8

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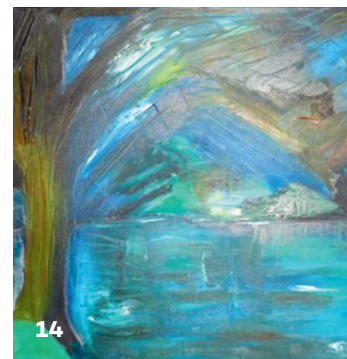
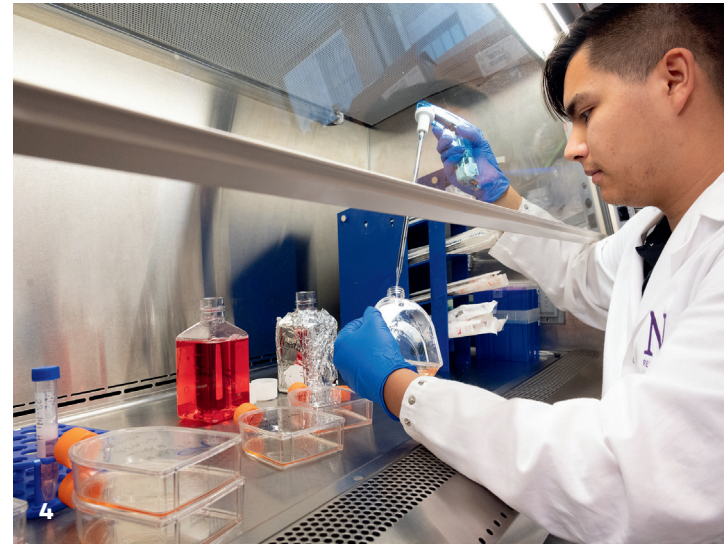
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**ON THE COVER**

SuperAger Helen Chan joined us in June to celebrate 25 years of SuperAging! Discover more on page 8.



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“We continue to make progress in understanding the devastating dementias that we study and moving toward treatments, as well as gleaning insights into SuperAgers, individuals with superior cognitive aging.” **ROBERT VASSAR, PHD**

### Dear Friends and Colleagues:

*It has been an amazing year for the Mesulam Center! Research in the Center has been thriving, and the multidisciplinary team at the Neurobehavior and Memory Clinic continues to diagnose, treat, and care for persons living with dementia.*

We continue to make progress in understanding the devastating dementias that we study and moving toward treatments, as well as gleaning insights into SuperAgers, individuals with superior cognitive aging. This year marked the 25th anniversary of the Northwestern University SuperAging Program (NUSAP). On June 5, we honored the SuperAgers with a special celebration at Northwestern to thank them for their participation in our program and tout their incredible resistance to the effects of brain aging. The ingredients for making a SuperAger are mysterious, but we are making progress. For example, we know that as a group, they are very social and young at heart. They also have unique features in certain areas of the brain important for social interactions and memory functioning. Moreover, they are resilient to the effects of Alzheimer’s pathology – the amyloid plaques and tau tangles. We are excited about our research with the SuperAgers and look forward to uncovering more of the secrets of their cognitive success. Onward!

In addition to NUSAP, the Mesulam Center has been very active in other areas of research, patient care, and community engagement. There has been new focus around the world on primary progressive aphasia (PPA), which was discovered by Dr. Marsel Mesulam in 1982. PPA is a clinical syndrome that results in the impairment of language, called aphasia. More attention has been on PPA of late because of the recent announcements that celebrities Bruce Willis and Wendy Williams were both diagnosed with this disease. In the wake of these reports, Drs. Ian Grant and Sandra Weintraub discussed PPA with the news media to promote awareness of this neurodegenerative disorder. The Mesulam Center continues to be a leader in research on PPA and has published several studies on PPA this past year.

The author Hans Christian Andersen once said, “Where words fail, music speaks.” Indeed, the Mesulam Center Music and Medicine Program, led by Dr. Borna Bonakdarpour, helps people with dementia find a way to “speak” even though their language and cognition are impaired from disease. These patients report enhanced emotional state, decreased tension, reduced restlessness, and increased pleasure. I hope you’ll read more about this groundbreaking work in this issue.

Research in the dementia field has traditionally focused on studying individuals of Caucasian European ancestry. Although we have learned enormously from this work about the genetic and environmental factors that associate with dementia in white populations, we know far less about these factors in individuals of different ancestries and with different lived experiences. We recognize that dementia may look very differently in people of other racial and ethnic groups. Dr. Darby Morhardt and her team at the Mesulam Center have continued to work tirelessly to engage diverse populations, particularly the African American community, to raise awareness about brain health and

dementia and to recruit individuals of under-represented groups into our studies. Additionally, our Diversity, Equity, and Inclusion committee has been working to enhance equity and inclusion within the Mesulam Center. In these ways, we enhance the diversity of our research participants and Center to enrich our understanding of dementia across all ancestries.

It is also critical to increase the diversity of researchers themselves. This year, the Mesulam Center continued our Brain Scholars Program, led by Dr. Changiz Geula, where students from underrepresented groups are invited to tour the center and learn about the brain and dementia. Moreover, we chose our largest group of students yet to do summer internships and conduct research in the center. Although the Brain Scholars Program is still only in its first years, it is beginning to have its success stories. In fact, I am proud to report that one of the inaugural Brain Scholars, Antwan Howard, has been enrolled in a bachelor of science to medical doctor degree program and continued his work at the Center this past summer as a research assistant.

Drs. Mesulam and Weintraub started Alzheimer Day in 1994, and it has been the premier event of the Center ever since. This year marked the Mesulam Center’s 30th Annual Alzheimer Day, which you can read about in this issue.

I am pleased to welcome a new faculty member to the Center. Dr. Todd Parrish (radiology) has been appointed Imaging Biomarker Core Leader for our Alzheimer’s Disease Research Center. Dr. Parrish and his team are deepening our understanding of brain structure in the context of dementia but also in healthy normal aging and even SuperAging. We are thrilled to be working with him.

Exciting new developments in the dementia field have been made on other fronts this past year. July 2 saw the FDA approval of a new Alzheimer’s drug, Kisunla (the commercial name of the drug donanemab). Our Neurobehavior and Memory Clinic is working to get Kisunla up and running as a treatment option at Northwestern Medicine. You can learn more about Kisunla later in the newsletter.

All of us at the Mesulam Center look forward to 2025, hoping that it will be just as exciting. We always enjoy hearing from you. Feel free to contact me or any of my colleagues with comments or questions. Stay well and stay safe.

Warm regards,

**Robert Vassar, PhD**

Director, Mesulam Center for Cognitive Neurology and Alzheimer’s Disease  
and Davee Professor of Alzheimer Research

## Latest Research by Mesulam Center Faculty

Each year, Mesulam Center faculty and staff publish dozens of scientific papers on their cutting-edge research that seeks to better understand the neurodegenerative disorders that cause dementia. Here are several of these breakthrough studies that have been published in the past year.

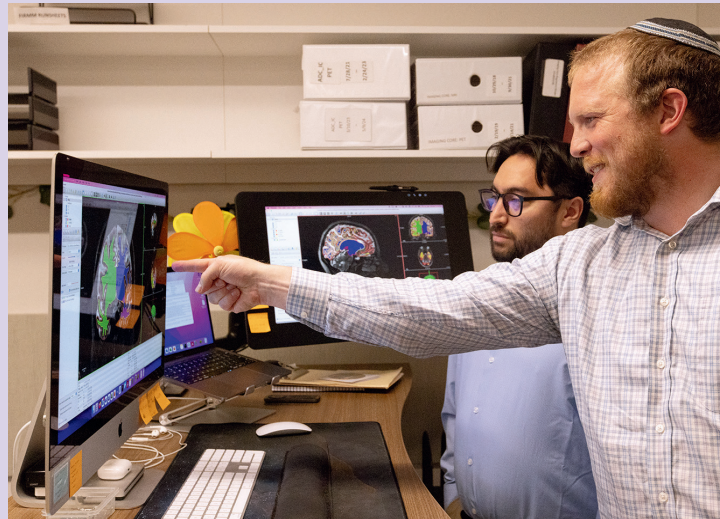
**“Measuring Multidimensional Aspects of Health in the Oldest Old Using the NIH Toolbox: Results from the ARMADA Study”**  
*Archives of Clinical Neuropsychology*, January 12, 2024

The National Institutes of Health (NIH) Toolbox is a computerized battery of tests assessing cognition, sensation, emotion, and motor functioning across diverse patient populations. However, the original comparison group only includes persons up to age 85, precluding its use in the oldest old. This study administered the NIH Toolbox to persons aged 85+ and compared their performance to those aged 65–84. As expected, scores on certain tests of cognitive, motor, and sensory functions decreased with age in the oldest old, especially tests that rely heavily on attention and rapid processing. Results support the use of the NIH Toolbox in persons over 85 with normal cognition.

Authors: **Molly Mather**, Emily Ho, Katy Bedjeti, **Tatiana Karpouzian-Rogers**, Emily J. Rogalski, Richard Gershon, **Sandra Weintraub**

# 86

Total number of publications from Mesulam Center researchers, September 2023 – August 2024



Joshua Pasaye (left) and Daniel Gustein (right) review brain scan images.

**“Phenotypically concordant distribution of pick bodies in aphasic versus behavioral dementias”**  
*Acta Neuropathologica Communications*, February 22, 2024

Frontotemporal lobar degeneration caused by tau protein (FTLD-tau) is a neurodegenerative disease diagnosed after death. This study looks at Pick’s disease (PiD), a subtype of FTLD-tau, and its effects on primary progressive aphasia (PPA) and behavioral variant frontotemporal dementia (bvFTD). Both conditions can arise from PiD, impacting language and personality. The research focused on how PiD spreads in the brain and

its connection to symptoms. Results showed that PiD was linked to clinical symptoms, with bvFTD having more damage in behavior-related areas and PPA in language areas. The hippocampus also showed significant PiD damage, raising questions about its vulnerability.

Authors: **Allegra Kawles**, **Rachel Keszycki**, **Grace Minogue**, **Antonia Zouridakis**, **Ivan Ayala**, **Nathan Gill**, **Alyssa Macomber**, **Vivienne Lubbat**, **Christina Coventry**, Emily Rogalski, **Sandra Weintraub**, Qinwen Mao, Margaret E. Flanagan, **Hui Zhang**, **Rudolph Castellani**, **Eileen Bigio**, **M-Marsel Mesulam**, **Changiz Geula**, **Tamar Gefen**

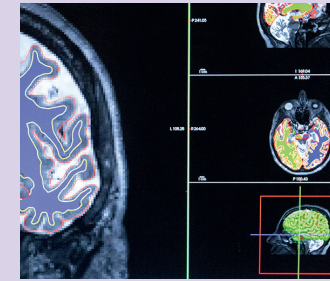
**“Loss and microglia phagocytosis of synaptic proteins in frontotemporal lobar degeneration with TDP-43 proteinopathy”**  
*Neurochemistry International*, March 5, 2024

Nerve cells communicate through synapses, small junctions that are crucial for brain function. Loss of synapses is a key feature of some dementias, like Alzheimer’s disease. However, research on synapse loss in frontotemporal dementia (FTD) has been limited. This study aimed to investigate synaptic proteins in FTD with TDP-43 accumulation (FTD-TDP). We found decreased levels of two synaptic proteins in FTD-TDP compared to normal brains, while a third protein was increased. This suggests a potential response to damage. Additionally, we observed increased microglia, the brain’s immune cells, that may be removing synapses excessively, indicating a link between microglia and synaptic loss in FTD-TDP.

Authors: **Ivan Ayala**, **Atousa Bahrami**, Yuting Pan, **Callen Spencer**, Margaret E. Flanagan, **M-Marsel Mesulam**, **Tamar Gefen**, **Changiz Geula**



Researchers at the Mesulam Center study human brains to deepen our understanding of cognitive decline.



Brain scans offer researchers a holistic picture of cognitive function.

**“Cognitive functioning in patients with neuro-PASC: the role of fatigue, mood, and hospitalization status”**  
*Frontiers in Neurology*, June 27, 2024

This study examined cognitive performance in patients at a large Neuro-COVID clinic who experienced brain fog but showed low-normal cognitive test scores. The authors compared performance between hospitalized and non-hospitalized long COVID patients and analyzed the relationship between self-reported symptoms of cognition, mood, and fatigue with cognitive outcomes. This is the first study to focus on cognitive performance in long COVID patients reporting brain fog, using a population designed to detect impairment. Surprisingly, the findings showed little additional cognitive impairment, with participants scoring in the low-normal range. Cognitive performance did not correlate well with self-reported cognitive symptoms, but mood and fatigue did.

Authors: **Joshua Cahan**, John-Christopher Finley, Erica Cotton, Zachary Orban, Millenia Jimenez, **Sandra Weintraub**, Tali Sorets, Igor Koralnik

**“Proposal for a Mechanistic Disease Conceptualization in Clinical Neurosciences: The Neural Network Components (NNC) Model”**  
*Harvard Review of Psychiatry*, July 1, 2024

This article proposes a new framework to understand the mechanisms behind behavioral presentations. The neural network components (NNC) model could guide the development of a mechanism-based disease classification, improve the understanding of underpinning pathology, and provide specific targets for treatment. This model could dissolve the artificial barriers between the fields of psychiatry and neurology.

Author: **Malik Nassan**

**“Cerebral amyloid-β-related angiitis and iatrogenic cerebral amyloid angiopathy-related vasculitis: Implications for amyloid-related imaging abnormalities”**  
*Journal of Neuropathology & Experimental Neurology*, July 5, 2024

Anti-amyloid drugs such as lecanemab sensitize amyloid to the immune system. Substantial amyloid often “lives” in the walls of blood vessels and are thus targeted by the drug, resulting in toxicity, such as edema, hemorrhage, neurological signs, and sometimes death. A similar, very rare process exists in nature, in which an immune response is directed against amyloid in blood vessel walls. This brief article highlights the similarities between anti-amyloid drug toxicity and a natural condition called

# 15

Grants received by the Mesulam Center September 2023 - August 2024

# \$4.7M

Grant funding received by the Mesulam Center September 2023 - August 2024

cerebral amyloid angiopathy-related inflammation. Such a process may explain in large part the phenomenon on MRI known euphemistically as “amyloid-related imaging abnormalities,” or ARIA.

Authors: **Rudy Castellani**, **Pouya Jamshidi**

**“Progressive verbal apraxia of reading”**  
*Cortex*, July 6, 2024

In this single case study, we describe a novel clinical syndrome called “Progressive Verbal Apraxia of Reading,” defined by an isolated, progressive difficulty in reading words aloud. While the ability to convert letters into sounds was intact, difficulties during reading and not during spontaneous speech. Neuroimaging showed reduced brain volume and metabolism in the right posterior cerebellum, suggesting that a disconnection of this region from the cerebral cortex may underlie this new syndrome.

Authors: **Elena Barbieri**, Joseph Salvo, Nathan Anderson, **Sarah Simon**, **Lauren Ables-Torres**, **Michelle Los**, **Jordan Behn**, **Borna Bonakdarpour**, Ania Holubecki, Rodrigo Braga, **M-Marsel Mesulam**

**“The role of the gut microbiome in the regulation of astrocytes in Alzheimer’s disease”**  
*Neurotherapeutics*, July 24, 2024

Alzheimer’s disease (AD) is the most common neurodegenerative disorder and the leading cause of dementia. It is marked by protein aggregates of amyloid beta (Aβ) and tau, along with progressive neurodegeneration. As these protein aggregates accumulate, a strong inflammatory response occurs in the brain, involving reactive support cells known as astrocytosis and microgliosis. Recent research has shown that the gut microbiome (GMB), which consists of trillions of bacteria in the human intestine, can influence both astrocytosis and microgliosis related to Aβ and tau. This review summarizes evidence on the GMB’s role in controlling reactive astrocytosis in Alzheimer’s disease.

Authors: Sidhant Chandra, **Robert Vassar**

Read more about these and all of our recent research publications at [brain.northwestern.edu/publications](http://brain.northwestern.edu/publications).



## FDA Approves Alzheimer's Drug Donanemab: A New Milestone in Treatment

On July 2, 2024, the FDA approved Kisunla (donanemab), marking the second disease-modifying Alzheimer's drug to receive full approval. This follows the approval of Leqembi (lecanemab) in July 2023. Both drugs are groundbreaking in their ability to slow the progression of Alzheimer's disease by targeting and removing amyloid plaques from the brain. Clinical trials have shown that these therapies can reduce the rate of cognitive decline by about 25-30% over an 18-month period.

Though people on these drugs still experience cognitive decline, there is hope that earlier intervention might delay or even prevent the onset of Alzheimer's symptoms. Clinical trials, including those conducted at the Mesulam Center, are underway to explore whether these therapies could be effective as preventative measures. However, results are still a few years away.

"This approval marks a significant step forward in our fight against Alzheimer's," said Robert Vassar, PhD, director of the Mesulam Center. "While there is no cure yet, drugs like donanemab give us new tools to slow the disease's progression

and improve patients' quality of life. One day, we hope to see a whole armamentarium of therapies to use in combination to fight Alzheimer's, like the way we treat cancer, heart disease, diabetes, and HIV/AIDS."

The Northwestern Medicine Neurobehavior and Memory Clinic is working to offer donanemab as a treatment option for eligible patients. Like lecanemab, donanemab is administered via

"While there is no cure yet, drugs like donanemab give us new tools to slow the disease's progression and improve patients' quality of life."

**ROBERT VASSAR, PHD**

IV infusion and requires frequent monitoring through MRIs to check for potential side effects such as amyloid-related imaging abnormalities (ARIA). While these side effects are usually mild, they can sometimes be more serious, especially in patients with the ApoE4 gene or those on blood thinners.

Both drugs are covered by Medicare for patients enrolled in a National Patient Registry, but the out-of-pocket costs are significant. Donanemab is priced at \$32,000 annually, not including additional medical costs. For now, it remains essential that individuals consult their neurologist to determine if these new therapies are appropriate for them.

To learn more about these new therapies and how they may benefit you or a loved one, visit [brain.northwestern.edu/medications](https://brain.northwestern.edu/medications).



## Congratulations and Farewell to Dr. Reed

We extend our heartfelt congratulations to Deborah Reed, MD, who retired from the Northwestern Medicine Neurobehavior and Memory Clinic on September 30, 2024 after serving as a geriatric psychiatrist for 24 years. It is understatement to say that we will miss her personally and professionally.

Dr. Reed joined the clinic in 2000 and quickly became an integral part of our team, playing a pivotal role in establishing the clinic's multidisciplinary approach. Her dedication and expertise helped to make geriatric psychiatry a cornerstone of our practice. Her commitment to clinical excellence and her weekly participation in the Wednesday Clinical Rounds are just two examples of her remarkable contributions, which have left an enduring impact on our community.

In recognition of her transformative work, Dr. Reed's portrait will be proudly displayed in the founders' gallery in the Mesulam Center offices—a fitting tribute to her legacy.

Dr. Reed's retirement marks the end of an era, but thanks to her thoughtful mentorship, her patients will continue to receive the compassionate care they have come to expect. We are also delighted that she will now have the opportunity to pursue many of the personal projects she has long looked forward to.

Please join us in thanking and celebrating Dr. Reed for her exceptional service and wishing her all the best in her well-deserved retirement.

**Marsel Mesulam, MD**

Director, Northwestern Medicine Neurobehavior and Memory Clinic

Founding Director Emeritus, Mesulam Center for Cognitive Neurology and Alzheimer's Disease

## Faculty Profile: Todd Parrish, PhD



TODD PARRISH, PHD, professor of radiology and director of the Mesulam Center Imaging Core, is a brain cartographer. His life's work is mapping brains.

Attempting to study every nook and cranny of the brain, he looks at tissue, structure, and chemical composition. "Finding biomarkers that can predict how people are going to progress cognitively is an important thing to understand for treating people down the road," Parrish said.

His team helps develop and run studies to understand brain function at every stage of development. One project involves mapping brains of three-month-old children and imaging them over the course of their lives, until some of them potentially become SuperAgers — people who are 80 years old or older with the memory capacity of individuals 20 to 30 years younger.

"We span the whole range of people and their brains and look at all kinds of different components within it," Parrish said. Parrish called his and

fellow collaborators' efforts rewarding, seeing how the project has grown over the years.

"Dr. Mesulam, Dr. Ken Paller, Dr. Darren Gitelman, and I formed this cognitive brain mapping group to really try to understand functional imaging," he said. "Now, it's bloomed into something that allows all the faculty members to get together and understand."

Another irreplaceable part of Parrish's team is the lab's MRI devices, named Tuna and Tarpon after Parrish's love for all things fish. Even his office pays homage to his love for fish and teamwork. Framed front and center, his workspace's wall is adorned with crimson-colored cascades of fish swimming across the paper. Created by a pair of artists, the work embodies a team spirit and shows just how far a community can take a project.

In spring of 2024, he was named as the director of the Mesulam Center Imaging Core. Just hitting the tip of neuroimaging's iceberg, Parrish is looking forward to seeing how brain mapping continues developing through the Center. "We're not done discovering new uses for MRIs," he said. "The technical challenges are what keep me coming to work every day."

## Trainee Profile: Jane Stocks, PhD



JANE STOCKS, PHD, found her way back to the Mesulam Center after working alongside Sandra Weintraub, PhD, during her time as a clinical neuropsychology student.

Now a Florane and Jerome Rosenstone Behavioral Neurology Postdoctoral Fellow, her days are a 50-50 split between clinical work and research. Half of her time is spent at the Neurobehavior and Memory Clinic, where she interacts with patients and conducts neuropsychological assessments. And during the other half of her time, she calls the Center her home, conducting neuroimaging research with the primary progressive aphasia team.

Stocks loves her personal time in her office, running analyses and working through brain imaging, but she thrives on teamwork too. "My favorite part is collaborating with the neuropsychologists, the imagers, the research assistants, and just being part of such a wonderful interdisciplinary team," she said.

For her, the team extends beyond her colleagues and includes the patients, research participants, and caregivers. "You can't understand the lived reality of neurodegenerative diseases without working directly with patients and their families," Stocks said. "That really motivates you and provides such important context into the types of research questions that we should be asking."

If Stocks could go back to her first day on the job, she would share the lessons she learned along the way. "Step outside of your office," she said. "And don't be afraid to have lots of conversations. We work with such esteemed clinicians and researchers that it can be hard to just strike up a conversation or suggest a collaboration. But that's where the magic of the Center comes from: in a question lobbed across the hallway, or poking into somebody's office and saying, 'What do you think about this finding?'"

"You can't understand the lived reality of neurodegenerative diseases without working directly with patients and their families."

**JANE STOCKS, PHD**



# Physically 80 but Mentally 50: Celebrating 25 Years of SuperAging at Northwestern

Early in her career, Sandra Weintraub, PhD, wanted to understand the aging brain after she saw how thinking abilities and memory change in people as young as 40. Initially, she wondered how people like musician Pablo Casals and psychoanalyst Anna Freud, who were “vibrant and cognitively intact” in their old age, deviated from the norm.

Weintraub, professor in the Department of Psychiatry and Behavioral Sciences at the Mesulam Center, soon realized that maybe extreme memory loss wasn’t all there was to aging. “Noticing that not everyone loses their cognitive abilities when they get older, I wanted to try to understand what makes a difference,” she said.

Wonder turned into a reality when Weintraub and Marsel Mesulam, MD, founding director emeritus of the Mesulam Center, discovered more people well into their 80s who functioned mentally as though they were 60 or younger.

This is when they coined the term “SuperAgers,” adults over 80 who have the memory capacity of individuals 20 to 30 years younger. They founded the Northwestern University SuperAging Program (NUSAP), hoping to learn more. Twenty-five years later, the program led to similar studies across the nation — all of which want to understand this rare kind of mental aging.

## Social and young at heart

NUSAP “came naturally out of studying brains,” said Molly Mather, PhD, assistant professor and clinical neuropsychologist at the Mesulam Center. Ultimately, the question driving the study became: What’s allowing people to be this high functioning well into their 80s?

Mesulam and Weintraub first saw this phenomenon when studying brains from individuals who had participated in a longitudinal study at the Miami Brain Endowment Bank. The study, in collaboration with bank founder Deborah Mash, revealed interesting differences.

“We were tracking people who did not have cognitive impairment, and we discovered that we had some SuperAgers,” Weintraub said. But SuperAgers were not common, and the team did not see any hardline lifestyles that led to becoming one.

“Some don’t smoke, some smoke cigars every day, some don’t drink, some drink whiskey every day, some don’t exercise, others exercise,” Weintraub said. “There’s no single pathway to this SuperAging phenomenon.”

There is one thing SuperAgers had in common: they are social and young at heart. “One time I was sitting in my office, and my research assistant came running in and said, ‘You’re not going to believe this. Mrs. X is doing a handstand in my office,’” Weintraub said.

## Two different pathways in SuperAger brains

NUSAP participants give blood samples and undergo brain imaging and often donate their brains after they die. This led to some important insights. “One big thing we found is that in everybody over 65, no matter how cognitively intact they are, their brain starts manufacturing the Alzheimer proteins — amyloid and tau,” Weintraub said.

Sometimes amyloid and tau buildup led to Alzheimer’s dementia, and other times, like in SuperAgers, it was not associated with cognitive impairment at all, she said. But very high amounts of neurofibrillary tangles, or a buildup of irregularly folded tau protein — one of the two proteins implicated in Alzheimer’s disease — are associated with cognitive decline and dementia.

Some tau buildup is considered typical with age, but no buildup is rare. Seeing this, the team categorized their findings into two different pathways. Some SuperAgers don’t manufacture these proteins and show resistance to them. Others produce them, but the proteins’ presence has no impact on cognition. These SuperAgers show resilience to the proteins. However, people who are protein-resistant are much rarer, Weintraub said.



## Recruiting more participants across cultures

The team is now focused on recruiting participants from different backgrounds to better understand what leads to these different pathways and cognitive aging outcomes. “There needs to be diversity in the sample because people in different cultures age differently,” Weintraub said. “There are different beliefs, different support for aging, and different socioeconomic factors.”

Fully understanding the mechanisms for this atypical aging pathway is still far away, Mather said. “We still don’t know why someone might be a SuperAger versus not,” she said. “But I think this is all part of understanding the spectrum of trajectories that you can have with aging.”

SuperAging capabilities and dementia diagnoses are extremes at either end of the cognition scale. That means “dementia is just not normal aging,” Weintraub said. “It’s a loss that interferes with your ability to take care of yourself.”

Understanding how someone behaved at their cognitive peak is relevant to aging outcomes, so the best thing anyone can do is take their well-being into their own hands, Weintraub said. “Everybody should get their cognition tested when they’re in their 50s, so you have a baseline,” she said.

In June 2024, the Mesulam Center hosted a celebration of 25 years of NUSAP, honoring the people that keep the study alive. More than 45 SuperAgers attended.

“We wanted to bring people together to thank them, to celebrate their participation, and to kiss COVID goodbye,” Weintraub said.



## ARE YOU A SUPERAGER?

Do you think you or someone you know is SuperAger? Visit [brain.northwestern.edu/superaging](https://brain.northwestern.edu/superaging) to learn more.

## 25 YEARS OF SUPERAGING

**1987:** Mesulam writes a commentary on why age doesn’t have to be associated with cognitive decline.

**1994:** Weintraub’s study finds cognitive decline in aging physicians, but those 65+ matched younger residents’ performance.

**1997:** Mesulam’s work with Mash finds resilience in an 81-year-old’s brain, inspiring a study on cognitive resilience to aging.

**1999:** Northwestern researchers coin the term “SuperAger” to describe persons 80+ with exceptional episodic memory.

**2001:** The study protocol focusing on SuperAging is submitted to the Northwestern Institutional Review Board.

**2004:** Researchers find Alzheimer’s tau in the nucleus basalis correlates with cognitive scores in older adults.

**2005:** The Northwestern University SuperAging Program (NUSAP) is initiated, enabling local brain donation for research.

**2006:** NUSAP gets an initial pilot grant from the Davee Foundation to continue study of SuperAgers.

**2012:** The first paper on NUSAP participants details unique brain signatures distinguishing SuperAgers from control participants.

**2013:** NIA grants support longitudinal SuperAging research at Northwestern, led by Rogalski, Mesulam, and Geula.

**2021:** The NIA awards multi-site grants to Northwestern and Boston University for SuperAging research.

**2023:** Rogalski joins the University of Chicago, expanding SuperAging research regionally with an NIA grant.

**2024:** NUSAP, led by Mesulam, Geula, Gefen, Weintraub, and Mather, continues at Northwestern with promising future directions.



# A Young Mind with an Old Soul's Calling to Neuroscience

Teenager Antwan Joel Howard finds his life's work at the Mesulam Center

## THE BRAIN SCHOLARS PROGRAM: LEARNING THROUGH DISCOVERY

The Brain Scholars Program is a Center initiative that introduces middle and high school students in Chicagoland to neuroscience through scientific experiments, brain examinations, and mentorship. Learn more at [brain.northwestern.edu/brainscholars](http://brain.northwestern.edu/brainscholars).



At a research center where the average investigator's age is above 30, one person became the exception. Antwan Joel Howard, 18, works in the Mesulam Center alongside minds decades older, learning about the science of disease and simultaneously connecting with study participants.

Howard initially joined the Mesulam Center team in the summer of 2023 as an intern in the Brain Scholar program, a Center initiative that introduces middle and high school students to neuroscience through scientific experiments, brain examinations, and mentorship.

However, this summer was different. Tamar Gefen, PhD, associate professor of psychiatry and behavioral neurosciences, saw that Howard's intelligence and wisdom was beyond his years. She was ready to bring him back for another summer — this time as a full-time researcher.

As a recent high school graduate, Howard has a passion for all things neuroscience. His grandmother, Gladys Howard, lit a fire under him from a young age. After graduating from Rush University, she became the first Black woman to work as an accountant at the University of Illinois Chicago. Howard envisioned success for her grandson. "She pushed me in this direct path to education that just overcame my life," he said. "Nothing could get in my way, no matter the obstacle."

Howard also saw how cognitive decline affected his loved ones at an early age. His grandmother's uncle was diagnosed with Alzheimer's. When he tapped into pockets of memories that were tucked away in his great uncle's mind, he was inspired to learn how the brain worked the way it did.

"I was able to show him pictures from the 70s and the 80s, of his mother and sister," Howard said. "He would still remember who they were. It made me think, 'So what's happening in his brain that's making him forget all this other stuff but remember this?'"

### Driven by curiosity

Howard's questions led him to the Mesulam Center. When many young adults his age were out soaking up the summer heat, Howard much preferred the luminescent overhead lights glimmering over plated brain tissue. His days were filled with learning genotyping and preparing Western blots, a laboratory technique used to detect a specific protein in a blood or tissue sample, processes which many are exposed to much later in college.

"Antwan had the curiosity of a much more advanced trainee," Gefen said. "His questions were on par with a graduate student or even a postdoc. He would sit down, and you could just see him exploding with excitement and passion. That kind of grit, that kind of curiosity is not something that you can train all the time."

Gefen secured Howard another summer at the Center after the National Institutes of Health (NIH) approved the grant for his return. His work at the Center went above and beyond science, according to Gefen. "He was able to connect with everyone. It was faculty, it was staff, it was students, and it was SuperAgers," Gefen said. "I think it was in part because you could just sense his commitment and his passion."

Howard formed long-lasting bonds with the entire community at the Center, especially with Edith Renfrow Smith, 110, the oldest SuperAger in the program and one of Chicago's oldest living residents. Even though the two were numerous generations apart, they bonded on their education at Xavier University, a Historically Black College, and life's simplest pleasures.

"We were all asking Edith questions like, 'What was the most difficult time of your life?'" Gefen said. "And Antwan turns to her, and we're all really excited about what he's going to ask. He asked, 'What is your favorite pie to make?'"

Howard's ability to connect transcended his age that day: he was an old soul with a young mind who resonated with a young-at-heart soul's years of wisdom.

### Passing knowledge to the next generation

Combining the confidence his team saw in him with the opportunity to work with brains, Howard said the serendipity of it all was not lost on him. "The thing that causes me to be as great as I am, to have the ideas I have, and to do the things that I do is up here," said Howard pointing to his brain. "And it's also what I'm working with — what I'm holding in my hands."

## THE BRAIN SCHOLARS PROGRAM: A COMMUNITY-ACADEMIC EXPERIENCE

204

Students hosted at the Mesulam Center in 2024

60

High school students

159

Junior high students

6

Students (2 high school and 4 middle school) participated in the summer 2024 internship

6

Visits to Northwestern labs since program inception

3

Visits to a local school (St John de la Salle)



There were moments Gefen learned from Howard, too. "He asked questions like 'What is Alzheimer's disease?' We were forced to start from the beginning to explain it in a way that's digestible," Gefen said. "We learned how to come together and pour our resources into a single person and watch that person grow."

Howard took a note from Gefen's playbook. "Now there's a standard, not only that I've set for myself, but for the people who are coming after me," he said. "I have to make sure that they feel they belong, no matter their age."

Howard, now a first-year neuroscience student and a direct medical school admit at Xavier University of Louisiana, is well on his way to becoming a researcher, doctor, and more importantly, a mentor mirroring his own. "Don't be afraid to show who you are and your gifts," he said. "Don't keep them to yourself, and don't let the things you know impact the things you do."



# First-of-its-kind Framework for Standardizing Dementia Nomenclature

The Dementia Nomenclature Initiative (DeNomI) published a paper in *JAMA Neurology* in 2023 proposing a framework that can be used to communicate information about age-related cognitive disorders and their causes.

An “accidental advocate” is how Angela Taylor described herself, when it came to cognitive impairment disorders.

The vice president of strategic partnerships at the Lewy Body Dementia Association stumbled into her role through her father’s experience with dementia. “When my dad got diagnosed...all we knew was that the doctor said he had mild cognitive impairment,” Taylor said. “When the doctor said it wasn’t Alzheimer’s disease, we thought we dodged a bullet.”

However, Taylor’s father was diagnosed with the second most common form of progressive dementia: Lewy body. At every turn, she realized no one was familiar with the disease or understood what she was going through.

Taylor wasn’t alone in her struggle. Stigma, naming inconsistencies, and a lack of education have historically compromised research and therapy development for dementia, according to the National Alzheimer’s Project Act (NAPA). NAPA supported the establishment of a committee in 2016 to form a Dementia Nomenclature Initiative (DeNomI), a nationwide plan to address limitations in communicating dementia diagnoses and increase the general public’s understanding of diseases that cause dementia.

Sandra Weintraub, PhD, associate director of the Northwestern Alzheimer’s Disease Research Center, led one of three stakeholder work groups in creating a framework to clarify terms related to symptoms (e.g., cognitive impairment) and their causes (e.g., Alzheimer’s). The team spoke about the importance of establishing a standardized naming system for scientists and physicians, which also helps educate the community on the differences between cognitive diseases.



## Understanding where miscommunication happens

Ronald Petersen, MD, PhD, co-chair of the DeNomI project and director of the Mayo Clinic Alzheimer’s Disease Research Center, realized that various cognitive diseases and terms associated with dementia were “used inconsistently” by patients, families, doctors and even the research community.

“It was clear that we were not all talking the same language, even though we were on the same committee,” Petersen said.

The team’s solution: designing a study to understand how patients, clinicians, and researchers describe cognitive diseases. This included understanding where the miscommunication was happening, especially when differentiating between Alzheimer’s disease and dementia.

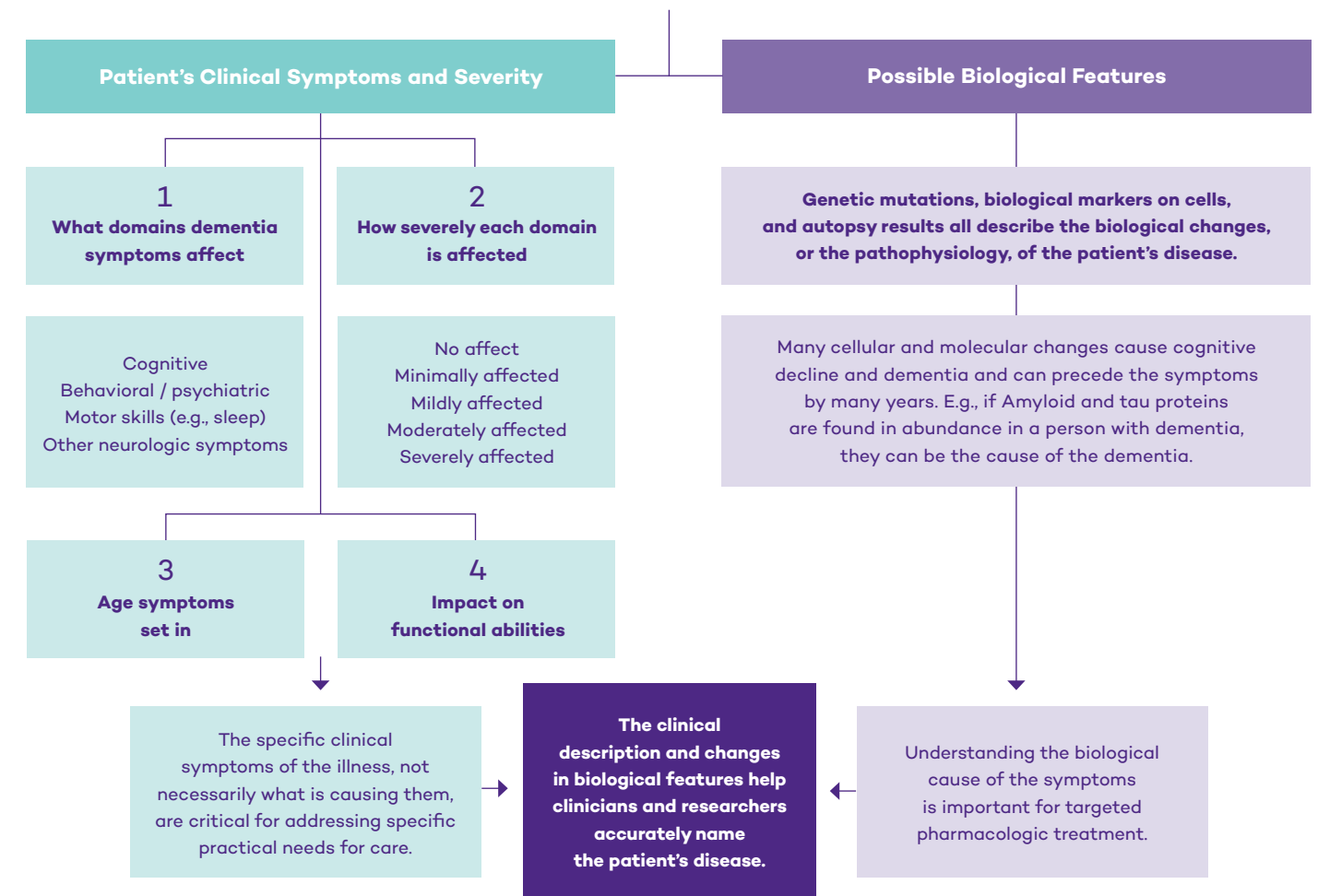
“We’ve been doing a disservice to our patients by using terms loosely and inconsistently,” Petersen said. “I think it behooves us as clinicians to state how exactly we’re using the term Alzheimer’s disease.”

The initial study also helped the team prioritize racial and ethnic underrepresentation, since such exclusion has limited clinical care to majority white and upper-middle-class individuals, according to the publication.

Through the team’s initial focus groups, they found that many people had more comfort around hearing disease labels than hearing the term dementia. But DeNomI isn’t trying to “fight” changing dementia nomenclature right now. The current push is to understand where existing names come from, according to Weintraub.

It boils down to understanding what words individuals use to describe how the disease

## DEMENTIA NOMENCLATURE INITIATIVE PROPOSED FRAMEWORK



expresses itself and how the symptoms are caused by the physical changes in their brains, Weintraub said. Understanding the differences between these categories led researchers to create a framework for future testing — one that separates the symptoms from the biology. “The public is now very educated on the difference between HIV versus AIDS and coronavirus versus COVID-19,” Taylor said. “What we don’t have is an understanding between dementia and diseases that cause it.”

## Testing the framework across communities

“Passionately obsessed” with wanting people to understand the relationship between the two concepts, Weintraub remembered why she set out with this task force to begin with — to help her patients.

“You guys got to do this for me,” said Weintraub when describing a trial participant interaction. “What’s wrong with me? Do I have a disease? Do I have a disorder?”

The DeNomI team also realized it was critical to understand dementia descriptors across

linguistic and cultural barriers. “Terms like dementia are not only pejorative, but they mean different things in different languages,” Weintraub said. “If you say, ‘You have dementia’ to somebody who speaks Spanish, you’re telling them they’re crazy.”

In the next phase, DeNomI plans on launching a pilot study to see how they can bring the framework into physicians’ offices. A key part of this process is recruiting ethnically and socioeconomically diverse communities and testing sites. The pilot will use the

established framework to do pre- and post-interviews in the next phase of the project.

The team hopes to gauge how well the framework works by evaluating how much patients, families, caregivers, and clinicians’ understandings change after the post-interviews, Weintraub said.

“If we can increase the awareness of people’s use of these terms to ask, ‘How am I using this term?’ Then getting people to just stop and introspect will be a success in itself,” Weintraub said.





Artist unknown



Peter Kay



Linda Lloyd

## With Primary Progressive Aphasia, Artistic Talents Can Flourish

Christina Ann Coventry, MSN, RN, spent her time at the Mesulam Center with people living with primary progressive aphasia (PPA) — a rare dementia syndrome that affects a person’s language.

During her tenure at the Center, Coventry tested clinical trial participants, recruited them, and learned the ins and outs of their lives. But one participant left a lasting mark on Coventry.

“She would create these beautiful, giant paintings,” Coventry said. “She did them well up until she couldn’t speak at all, but she was still doing this. Making artwork.”

In fact, it is not uncommon for artistic talents to flourish after a PPA diagnosis. Some people living with a diagnosis use it as an outlet for communication.

### What is primary progressive aphasia (PPA)?

PPA is not one disease. It is a syndrome, said Marsel Mesulam, MD, founding director emeritus of the Mesulam Center and Ruth Dunbar Professor in Neuroscience and Neurology. Several diseases can potentially result in PPA.

“There are three, four, five kinds of PPA,” Mesulam said. “And there are about ten diseases that lead to PPA, so in a ten by five matrix, there are a lot of combinations.” Mesulam first identified PPA as a syndrome in 1982, and it is often referred to as Mesulam’s syndrome.

Understanding how PPA affects communication is a team effort at the Center. Elena Barbieri, PhD, research assistant professor of physical medical and rehabilitation at the Mesulam Center,



D.W. Foote



Linda Lloyd

“When persons living with aphasia are working with these mediums, they get to exist in a space where the issues they’re having with language don’t really play a role. I do think when you create art, the materials lead you.”

**MICHELLE ANNE LOS, MS, CLINICAL OPERATIONS MANAGER AND PPA TEAM LEAD AT THE MESULAM CENTER**

an aphasia diagnosis. When asked to point to one of the three, people living with aphasia cannot associate the word with the object, Barbieri said.

### Where words fail, art speaks

Woodworking, glassblowing, painting, sculpting, and photography are just a few of the skills individuals living with PPA have honed in on early in their diagnosis. Despite a loss of communication abilities, or rather in light of it, people’s interactions with their environment increase, Mesulam said. The disease doesn’t give individuals new talents. Instead, they are nonverbally “re-routing their talents and engagement with the world,” he said.





Renee Stacey



DW Foote



Artist unknown

Even writing becomes an outlet. “I know a participant here who always wanted to write a novel, and then when he started developing PPA, despite the difficulties with language, he wrote and published it,” Barbieri said.

Individuals can experience other heightened non-verbal habits too. Becoming a Sudoku expert, putting together 3,000-piece jigsaw puzzles, and breeding pigeons is not uncommon, Mesulam said.

Individuals’ intensified “preoccupations” allow them to be flexible, so they can switch how they communicate, Mesulam said. “Because the involvement of the brain is limited, they really hang onto some of these non-verbal means of expression with a vengeance,” he said. “If one road is blocked, then they try to find some other way.”

In the short-term, these hobbies fill the lives of those with PPA, Barbieri said. “Getting recognition from other people — clinicians and family members I imagine — calms their increasing struggles,” she said. Partners find comfort and a way to be distracted from the disease through these preoccupations, too.

Often spouses’ small actions help their partners more than they can imagine. And eventually, individuals’ support systems became the Mesulam Center’s backbone. “We’re part of the same team,” Mesulam said. “Their families’ contribution to this research is priceless. We can’t do it without them.”

To this day, individuals’ photographs, paintings, and even a patchwork quilt adorn the Mesulam Center’s walls — a reminder of PPA participants’ resilience until the end. “They live on in our work,” Coventry said.

#### WANT TO SEE MORE?

Would you like to see more artwork from our PPA participants? Visit [adobe.ly/4hAoWkl](https://adobe.ly/4hAoWkl) to view the full art gallery.

### AN ARTIST’S JOURNEY NAVIGATING LIFE AND COMMUNICATION AFTER PRIMARY PROGRESSIVE APHASIA DIAGNOSIS

Carla Watson had a long career as a head bank teller and a supervisor at Navy Federal Credit Union, but she also had a passion for art.

She developed a deep interest in art from a young age. “When I was little, I would draw on my brother’s pant leg,” she said. “And when I got into school, I always took art classes.”

Through every phase of life, art was a constant for her. In fact, being diagnosed with a rare cognitive syndrome called primary progressive aphasia (PPA) was not enough to stop her either. Watson, a person living with PPA, and her husband, Duane Watson, spoke to the Mesulam Center about her struggles and triumphs through her journey with the syndrome.

For Watson, art always brought joy. “Being able to give it [the painting] to the person makes me happy,” she said. “I was able to do it for them for whatever reason they needed.”

While art remained a constant, her ability to verbally communicate started to fall short nine years ago. She began to notice it while talking to her husband Duane. “I would be talking, and all of a sudden, I couldn’t remember the word,” she said. “And it was something I should have remembered.”

Eventually, Watson went through an “extensive battery of neurology testing” in 2021, but she did not receive a conclusive diagnosis, Duane said. “You’re talking about a woman who was a head bank teller,” he said. “She always got commendable remarks on the job, so there was something going on.”

Ultimately, Watson was diagnosed with PPA. “We were just ecstatic to put a name to what she was experiencing and understand what she was going through,” Duane said.

But soon enough, “the reality of it all started settling in,” Duane said. Language impairments, which appear gradually at first, can compound over time. This can lead to changes in memory, judgment, attention, and personality. Additionally, the condition has no cure. Despite the definitive diagnosis, Duane continued searching for resources.

“I started looking and trying to find things because I thought there’s got to be something,” he said. “That’s when I found the Mesulam Center.” Watson’s journey through the Center helped her identify resources such as speech therapy, after she was successfully enrolled into the Language in Primary Progressive Aphasia Study.



#### A GIFT FROM THE HEART

Top: Carla and Duane Watson enjoy a meal at a local restaurant. Bottom: Mesulam Center staff stand with a painting gifted by Watson to the Center.

Practicing word association strategies with peers and loved ones helped Watson take control over her language skills again. The Mesulam Center continues to be a valuable resource and support system for the couple, Duane said.

“Carla has always said that she just wants to participate so that she could possibly get better,” he said. “But moreover, she hopes to give them the knowledge so that the Center can potentially come up with a viable treatment for PPA.”

While the Center provides Watson with a support system, she continues to give back through her gift — art. Her favorite painting found its home at the Center, after Watson gifted it to Marsel Mesulam, MD, founding director emeritus of the Mesulam Center.

“Carla got very moved,” said Duane, when describing her reaction to Mesulam receiving the painting. “She was on the verge of tears, and it was more from happiness than anything else.”

“I started looking and trying to find things because I thought there’s got to be something. That’s when I found the Mesulam Center.”

DUANE WATSON



# A Multidisciplinary Approach to Cognitive Healthcare

**The Neurobehavior and Memory Clinic brings specialists together to help individuals navigate their experiences.**

The Mesulam Center, home to the Northwestern Medicine Neurobehavior and Memory Clinic, has a unique philosophy embedded in every aspect of its practice — cognitive healthcare must be approached through a multidisciplinary outlook.

Bringing specialists together from numerous fields under one roof was the brainchild of Marsel Mesulam, MD, founding director emeritus of the Mesulam Center and Ruth Dunbar Professor in Neuroscience and Neurology.

Mesulam built an environment for a continuously growing healthcare team, making them “more than a medical practice,” he said. It is an integrated approach involving medical care, neuropsychology, nursing, and social work. The Clinic’s foundation is built on what Mesulam calls “therapeutic encounter.” This means caring for individuals, helping enroll them in clinical trials, and offering them new programs and approaches that help them manage their experiences.

“We can’t just have participants be research subjects,” Mesulam said. “We have to give something back.”

**A well-rounded approach to care and support**  
Maureen Daly, PhD, is one of the clinical neuropsychologists on the team who helps individuals to understand their cognitive changes to pinpoint what exactly they are experiencing. “I think of neuropsychology as one piece of the puzzle,” she said. “We want to better understand other medical conditions, psychiatric conditions, and lifestyle factors that contribute to cognition.”

Daly meets with people from all different stages in their care journey. Some may have a diagnosis from cognitive testing, while others are still on their way to one. Her approach mirrors the Center’s dogma: develop a well-rounded understanding into who the individual is and what their unique struggles are.

“We want to understand what is long-standing versus what is a change for individuals,” she said. “And we get the input of friends, loved ones, and family members members to better understand what they’re observing.”

Carly Liebst, RN, found her calling when she joined the Clinic as its first nurse. She saw how integrating her role

helped support physicians, social workers, and most of all, those who need care.

“I think getting to know the patients and the family aspect is really unique,” she said. “These diseases are very different because they’re very personal. It not only affects the patient, but it really affects their family too. We provide them with almost a second family because the physicians know their patients so well.”

Liebst’s role in the clinic helped her find support through those who seek care, just as they have through her. “Knowing the patients recognize my voice and they know who I am is just really nice,” she said. “It makes me feel good to remember who I am and that I can give them support.”



## Learning to live with cognitive changes

Darby Morhardt, PhD, LCSW, Lauren Dowden, MSW, LCSW, and Kate Lucca, MSW, LCSW make up the social work component of the team.

“Our role is to help figure out how you’re going to live with cognitive changes long term and to look at the implications of a diagnosis

of a neurodegenerative disease on your life,” Morhardt said.

Each week, the entire team meets for a check-in and works with neurology, neuropsychology, and psychiatry to merge everyone’s perspectives together when tracking an individual’s progress. “It provides a really robust picture of their situation, as opposed to just one lens,” Dowden said. “You get to really see it from multiple views, which then clinically helps us understand patients.”

The Clinic’s specialists also help individuals through clinical trials, which can expose individuals to new therapies and allow researchers to test new approaches to care. The Clinic has created a nationwide participant network that has revolutionized clinical trial recruitment. Traditionally, internal center clinics feed into

## INTEGRATED CARE

*The Clinic team works together to provide compassionate and personalized care for individuals living with a diagnosis and their caregivers.*

trial enrollment, but the Clinic has widened its reach to include trial participants from 31 states.

By developing a circular system, the Clinic has seen participants seek out the Mesulam Center because of the specificity of its research. And increased trial enrollment has directly contributed to increased research funding.

From diagnostic work to social work, each specialty is a gear propelling the Neurobehavior and Memory Clinic forward. “The sum is more than the individual parts,” Mesulam said.

## THE NORTHWESTERN MEDICINE NEUROBEHAVIOR AND MEMORY CLINIC IS HERE TO HELP

Designed to meet the needs of those who experience memory loss or other symptoms of dementia and their families, the Northwestern Medicine Neurobehavior and Memory Clinic offers a comprehensive array of diagnostic, therapeutic, and innovative care that treats the whole patient and their family.

The dedicated clinical team includes behavioral neurologists, neuropsychologists, neuropsychiatrists, and clinical social workers from the Northwestern Medical Group.

### Treatment plans include:

- Evaluation of memory and other thinking abilities using specialized tests.
- Psychiatric evaluation and treatment for associated mood and behavior disorders.
- Assessment and follow-up care by behavioral neurologists dedicated to treating those with dementia.
- Disease education, counseling, and referrals to community support services.
- Opportunities to participate in cutting-edge research on Alzheimer’s dementia, frontotemporal dementia, and primary progressive aphasia.

For more information or to make an appointment, please call 312.695.9627 or visit [nm.org/memoryclinic](https://www.nm.org/memoryclinic)





# A Melodic Therapy

## Harnessing the power of music to treat anxiety in individuals with Alzheimer's and their caregivers

Music and medicine often walk in step with each other. Underneath their rhythms lies a truth many have heard time and time again: music is medicine.

Borna Bonakdarpour, PhD, assistant professor of neurology at the Mesulam Center, understands this connection between the two disciplines. In his lab, he fuses improvisatory music with interventional treatment for persons living with Alzheimer's and their families.

Working with individuals experiencing cognitive disorders — including memory problems, language difficulties, and visual processing — he transforms medicine into a symphony. “I came to this discipline because of language and music,” he said reflecting on his medical degree and minor in piano and musicology. “I wanted to cross both.”

He spoke to the Center about the importance of using music as interventional anxiety treatment for people with cognitive impairments and their care partners, and he reflected on his hope for a future where music and medicine become synonymous with each other.

## Healing with improvisatory music

In September 2023, Bonakdarpour's pilot study, “Clinical Improvisatory Music for Alzheimer's Disease Anxiety and Caregivers” (CIMAC), was published in *Frontiers in Neurology*.

Preliminary results showed that administering Clinically Designed Improvisatory Music (CDIM) reduced anxiety levels in individuals with Alzheimer's and their care partners.

During the study, participants received eight sessions of improvisatory music designed by the clinic. Both individuals with Alzheimer's and their care partners were then evaluated for post-session anxiety levels. Bonakdarpour and his team presented their first year's results at the American Neurological Association (ANA) meeting in Orlando this year. Their analysis showed a reduction in patient anxiety and a reduction in caregiver burden. They also saw a decrease in heart rate and blood pressure because of reduced anxiety and stress in both groups.

“One of our participants, who had a high degree of anxiety and very high blood pressure, felt less anxious after eight sessions,” Bonakdarpour said. “They shared that their mind was ‘clearer,’ making decisions much easier.”



“We believe that music, as a sonic tool and regardless of autobiographical memory, can modulate the state of the mind to ease anxiety and stress.”

**BORNA BONAKDARPOUR, PHD**

Once participants completed their sessions, they were provided with the music that they listened to during the study, so they could sustain the effects.

### An alternative to pharmacological treatment

The study was inspired by Bonakdarpour's passion for music. “We believe that music, as a sonic tool and regardless of autobiographical memory, can modulate the state of the mind to ease anxiety and stress,” he said.

He also wanted to understand alternatives to traditional interventions, which often focus on medication management. The medication

route, used alone, comes with risks of side effects and polypharmacy, or regular usage of five or more medications at the same time.

In the CIMAC study, he took a note from past research that used music as an intervention for individuals living with Alzheimer's, but he saw a gap in the field, since the majority of studies focused on later stage Alzheimer's. His focus shifted to early-stage Alzheimer's. He was curious to see how anxiety levels changed by treating participants in dyads — groups of two composed of one person living with Alzheimer's and their care partner.

“Music not only helps the patients, but it also helps the caregivers who are very commonly stressed out and burdened with the disease,” he said.

Bonakdarpour looks forward to the next two years of the study, hoping to continue prescribing music as treatment. “We're continuing to recruit more individuals with Alzheimer's disease and caregivers,” he said. “We're also waiting to collect enough functional magnetic resonance imaging (fMRI) data, so we have the power to interpret the results.”



## DISCOVER THE POWER OF MUSIC IN CARE

Interested in learning more about CIMAC? Visit [bornacogneurology.com/music-and-medicine-program](http://bornacogneurology.com/music-and-medicine-program).

## TOTAL ACTIVE RESEARCH PARTICIPANTS AT THE MESULAM CENTER:

391

10+ years of participation 95

5-10 years of participation 156

2-5 years of participation 90

<2 years of participation 50

## INTERESTED IN PARTICIPATING IN RESEARCH?

The Mesulam Center is currently enrolling for various research studies, including those on SuperAging and primary progressive aphasia (PPA).

### We are looking for:

- Individuals who are cognitively healthy and over 55
- Individuals experiencing mild memory problems, sometimes referred to as mild cognitive impairment
- Individuals who have been diagnosed with mild dementia (including Alzheimer's disease)
- Individuals from traditionally underrepresented racial and ethnic groups, such as Black, Latinx, Asian, and Indigenous communities
- Individuals with a high school diploma or less

Our research efforts lead to a better understanding of and future treatments for age-related cognitive decline and the diseases that cause it. Most of our research takes place at our Center located in downtown Chicago.

Learn more at [brain.northwestern.edu/join](http://brain.northwestern.edu/join).





## CONNECTING THROUGH MUSIC

Lenny Marsh leads a recent Music, Movement, and Community class at the Old Town School of Music. The program seeks to spark joy and connection for individuals living with early-onset dementia and their families through music and shared experiences.

# Music, Movement, and Community

### Local program sparks joy and connection amid early-onset dementia

Music is therapy. It is a way to let the notes of a nostalgic tune overpower everyday anxieties. Universally, it connects us.

One program embodies the heart of this idea by reintroducing music into

individuals with dementia's lives: the Music, Movement, and Community (MMC) program through Lorenzo's House, a non-profit organization empowering youth and families living with younger-onset dementia. The class, for both individuals living with dementia and their families, creates an environment where people can listen to music, dance to music, and play music together.

The program began nearly two years ago at the Old Town School of Folk Music through a collaboration between Diana Cose, founder of Lorenzo's House, and Lenny Marsh, a music teacher at the school.

"A friend of mine was diagnosed with early-onset dementia," Marsh said. "He happened to be one of the first people I met when I started working at the Old Town

School." Marsh found Lorenzo's House and saw an opportunity to combine his life's work with a way to reconnect with his friend.

After a successful first run, Lorenzo's House wanted to expand the program to Chicago's South Side. Last year, Lorenzo's House and the Mesulam Center extended the program to a second location at Bright Star Church in the Bronzeville neighborhood. The expansion was made possible through Northwestern's Racial Equity and Community Grant — a program designed to address racial inequities and work toward structural change through partnerships between community organizations and Northwestern representatives. The team was awarded the grant for a second year this past July.

Glennese Ray, partnership liaison at Lorenzo's House, was inspired to help with the program's expansion into Bronzeville. "The idea was to get families involved that are in the Black and Brown space... for those that are living with younger onset dementia," Ray said. "Lorenzo was a Black man. He was definitely part of a Black person's community. And Diana was trying to be thoughtful in the process of how we get folks under our umbrella. Why not help more people that look like her Lorenzo?"

### Listening to music and creating it too

The MMC group is made up of individuals whose long-term memories are affected. Marsh's programming is helping them dust off the cobwebs to what seemed like a lifetime ago. "It's old school," he said. "It's music from the 60s, 70s, and 80s, and they really have a sense of remembering those tunes. They enjoy going back and listening to those tunes, moving to them, and dancing with their partner or caregiver."

Leaning on tunes from the past, attendees use their environment to conduct a symphony. "That could be [through] your hands on buckets, or drumsticks on buckets, or even wooden spoons on pots and pans," Ray said. "It's creating music."

Eventually, the music seeps into participants' lives, offering a safe space to let go of anxieties and explore life through rhythm and sound. "Music is good for the soul," Ray said. "And to watch people, who sometimes may not be mobile or might not have the words anymore, with smiles on their faces, dancing and tapping their feet — [gives me] a warm and fuzzy feeling."

Ray remembered one couple that would light up at every gathering, despite the hardships they faced as a caregiver and person living with dementia. "She sings, and he gives her a beat," Ray said. "Watching them makes me feel like I'm in the right place."

Currently, the grant supports group meetings at the Old Town School of Folk Music on the 2nd (in-person only) and 4th (hybrid) Saturday of the month. "That core group really bonded and formed their own community and support system," Marsh said. Outside of meetings, attendees and their families have coordinated their own gatherings, such as meet-ups at the Lincoln Park Zoo and the Garfield Park Conservatory.

Marsh has changed through this program, too. He found his connection to music rejuvenated after seeing the change music has brought in attendees' lives. "I've really re-learned the importance of music," he said. "The power of music is phenomenal... It just brings such joy to my participants' faces."

### INTERESTED IN ATTENDING?

Music, Movement, & Community is a free, interactive experience where music and expression ignite joy. This is an inclusive and stimulating learning environment of personal connection and fun for families living with younger-onset dementia.

Classes are held on the 2nd (in-person only) and 4th (hybrid) Saturday of the month at the Old Town School of Folk Music (4544 N. Lincoln Ave, Chicago)

Learn more and register at [lorenzohouse.org/our-programs/healing-spaces](https://lorenzohouse.org/our-programs/healing-spaces).

"Lorenzo was a Black man. He was definitely part of a Black person's community. And Diana was trying to be thoughtful in the process of how we get folks under our umbrella. Why not help more people that look like her Lorenzo?"

GLENESE RAY





**ALZHEIMER DAY BY THE NUMBERS:**

470  
Registered Attendees

43  
Research Participants, Patients, and Caregivers

30  
Active Research Participants

71  
Research Posters Presented

22  
Community Partners Showcased at Resource Fair

# Mesulam Center Celebrates 30th Annual Alzheimer Day

**Event recognized scientific achievement and bringing awareness to early-onset dementia**

The Mesulam Center for Cognitive Neurology and Alzheimer’s Disease celebrated its 30th Annual Alzheimer Day on May 3, 2024, where researchers and community members gathered to learn about recent accomplishments in the field, early-onset Alzheimer’s, and community efforts to raise awareness for those experiencing cognitive decline.

The program began with a welcome address by Robert Vassar, PhD, director of the Mesulam Center and Davee Professor of Alzheimer’s Research. Clinical trial successes in understanding disease-modifying, amyloid amino therapies — such as lecanemab and donanemab

— have provided a “new hope for Alzheimer’s disease,” he said. “There’s much work left to be done, in therapeutic testing for dementia, and the Mesulam Center will continue leading the way.”

Vassar thanked the Center’s research participants and their families for their involvement in research. “They are true heroes, who give selflessly to understand the underlying biology of devastating dementia,” he said. “Our research would not be able to move forward without them.”

Guest lecturer Gil Rabinovici, MD, director of the Alzheimer’s Disease Research Center at the University of California, San Francisco, gave the event’s Mendelson Mendelson Lecture. He explained how imaging advances have helped detect

Alzheimer’s disease and change the course of patient management. “What we found was that amyloid PET [scans] had a profound impact on patient management,” Rabinovici said. “Key elements of patient management, like the medications they were prescribed, or how they were counseled about safety and future planning, changed in over 60% of patients.”

**Quality of Life Symposium**

The Miller Family Quality of Life Symposium focused on younger-onset dementia, which can have different symptom presentations, daily struggles, and challenges for both persons living with dementia and their family members.

**LEARNING FROM EACH OTHER**

*Clockwise from top left: Gil Rabinovici delivers the keynote Mendelson Lecture; Sandra Weintraub speaks at the Quality of Life Symposium;*

*Ajay Kurani discusses research findings during the Poster Session; Mesulam Center staff welcome attendees at event registration.*



## FORGING A NEW PATH

From left, Rachel Kaplan, JD, Rob Johnson, Rashad Johnson, Vickie Johnson, Darby Morhardt, PhD, LCSW, and Sandra Weintraub, PhD, discuss the realities of navigating life with a younger-onset dementia diagnosis during the Quality of Life Symposium.



## MARIE AND CARL DUNCAN PRIZE IN MEMORY DISORDERS RESEARCH

John Disterhoft, PhD, professor emeritus of Neuroscience, awarded the 2024 Duncan Prize to researchers studying dementia and Alzheimer's disease. The recipients for clinical and translational research were **Allegra Kawles, Rachel Keszycki, Alyssa Macomber, and Molly Mather**, and the basic sciences awardees were **Lynn van Olst, Nalini Rao, and Zacharia Cross**.

## SAVE THE DATE

**31st Annual Alzheimer Day**  
Thursday, May 15, 2024  
10:30 AM - 4:00 PM

Embassy Suites - Chicago Downtown River North

Featuring Mendelson Lecture by Allan Levey, MD, PhD, director of the Goizueta Alzheimer's Disease Research Center and Professor and Department of Neurology Chair at Emory University.

Read the most up-to-date event information and view videos and research abstracts from this year's event at [brain.northwestern.edu/RSVP](http://brain.northwestern.edu/RSVP)

"Symptoms represent where the disease is, not what it is," said Sandra Weintraub, PhD, professor of psychiatry and behavioral sciences at the Mesulam Center. Weintraub addressed how researchers can narrow down what part of someone's brain is affected by differentiating between cognitive symptoms, but this is only one step in a complete diagnosis.

Darby Morhardt, PhD, LCSW, research professor and clinical social worker at the Mesulam Center, spoke about the research and awareness needed around the younger-onset because of how "differential" and "broader the diagnosis" is than late-onset. "The challenge for families living with younger-onset dementia... includes difficulty obtaining a diagnosis," she said.

Diana Cose, founding executive director of Lorenzo's House, spoke about her personal experience with her husband's early-onset Alzheimer's diagnosis. Cose's struggle to find support and resources led her to develop a new community during her family's journey. In an open letter to her husband Lorenzo, she thanked him for allowing her to share their family's story with children and spouses all over the country experiencing the same.

That allowed her to turn "isolation and stigma to connection and strength."

A panel discussion with Rachel Kaplan, JD, Vickie Johnson, and Johnson's family followed. They shared their unique lived experiences navigating these diagnoses.

## Staff Profile: Kate LaFroschia



KATE LAFROSCIA, MPH, research project manager and team lead for the Clinical Core team, just celebrated her two-year anniversary at the Mesulam Center.

During her early days at the Center, she did not know what to expect when working in a clinical setting. But now she sees how her role connects researchers and research participants for a common goal: improving livelihoods for people with cognitive deficits and differences.

LaFroschia's day-to-day work involves keeping the Clinical Core team accountable. She tracks project goals and helps expand research participation for all research studies affiliated with our Clinical Core, including the Northwestern University SuperAging Program Study (NUSAP).

LaFroschia believes that without enrollment, there is no study, and so her responsibilities involve explaining research goals and impact to prospective participants.

"Research is so interesting," LaFroschia said. "People that want to be involved in research typically are doing it because they have family members that have a diagnosis, or they are really motivated to find a cure for a disease."

Working with families who are donating their loved ones' brains to research have been some of the most impactful experiences for her.

LaFroschia's master's in public health from the University of South Carolina helped her understand how social determinants impact cognitive health. "I've realized how important our Center's goal of recruiting more diverse groups is," she said.

LaFroschia shares her passion for clinical research with the rest of the Mesulam Center team. "I love the people I get to work with," she said. "I think everyone here is so passionate about what they do."

"Research is so interesting. People that want to be involved in research typically are doing it because they have family members that have a diagnosis, or they are really motivated to find a cure for a disease."

KATE LAFROSCIA, MPH

## Staff Profile: Jordan Behn



JORDAN BEHN, senior clinical research coordinator at the Mesulam Center, sees research as a journey and not a linear path ending at a destination.

"I think I could never really be a full head-down, data-analysis person," Behn said. "My favorite thing is working through technical problems with my colleagues, supervisors, and mentees."

Bringing research results to life, Behn crunches data for the Bonakdarpour Lab and the primary progressive aphasia team at the Mesulam Center. "I was interested in finding something a little bit more clinical, where the research I was doing was more directly and visibly being applied to help someone," he said.

Behn is usually involved in multiple projects at once. Analyzing neuroimaging data, dating back 20 years, and using electrode stimulation for activating brains are just some of his responsibilities.

Behn remembers one project involved mountains of data and "babysitting" a computer for four weeks straight. "There's always a new question to ask and to try to answer through the lens of this longitudinal data," Behn said.

"I really liked the organization around sorting data from all of these different participants, who've gotten all of these different scans, and who have all of these different language tests they've taken," he said.

All those days of sifting through data helped map the hundreds and thousands of points, so "anyone could look at this database" and find the answers they need, Behn said.

While data drives Behn, the research participants reminded him why his work is so important in the first place. "One participant wrote thank you cards for everyone... With language deficits, that must have been so hard for her," he said. "But she found a way to express gratitude to all of us," he said.

For anyone starting a new journey at the Center, Behn suggests diving in head-first. "Get involved as soon as you can," Behn said. "And just try stuff. There are so many different kinds of things you can be exposed to," Behn said.



## Center Faculty Share Knowledge and Expertise on Local, National, and International Stages

As the Mesulam Center's work continues to grow, Center faculty continue to take on leadership positions in Chicago and around the world.

### LOCAL

- **Lauren Dowden, MSW, LCSW** spoke on a panel at the 2024 Chicago Sister Cities International Social Services Conference in June 2024.
- **Darby Morhardt, PhD, LCSW**, served on the planning committee of the 2nd annual Release the Silence: RACE into Action Conference for Black/African American families living with dementia in Chicago in April 2024. **Dowden** also spoke on a panel.
- **Morhardt** was invited to co-chair the Alzheimer's Association's Annual Caregiver and Professional Research Symposium, held at Northwestern in November 2024.



### NATIONAL

- **Elena Barbieri, PhD**, appeared on the Research Renaissance Podcast to discuss primary progressive aphasia.
- Following the announcements of FTD diagnoses for two major public figures – Bruce Willis and Wendy Williams – several Mesulam Center faculty members, including **Ian Grant, MD** and **Sandra Weintraub, PhD**, discussed FTD on national media, including NBC, CBS, and CNN.
- **Allison Lapins, MD** and **Kate Lucca, MSW, LCSW** presented a poster at the Alzheimer's Association International Conference (AAIC) 2024 in Philadelphia, PA.
- **Molly Mather, PhD**, and **Sandra Weintraub, PhD**, delivered a virtual presentation on brain health for the Library of Congress in May 2024.
- **Mather** presented on "Clinicopathologic Concordance in Dementia Syndromes" in September 2023 for KnowNeuropsychology.
- **Mather, Janelli Rodriguez, Antonia Zouridakis, and Allegra Kawles** presented posters at the annual meeting of the International Neuropsychological Society in New York, NY in February 2024.
- **Darby Morhardt, PhD, LCSW** was invited to serve a four-year term on the Education Committee for the Association for Frontotemporal Dementia's (AFTD) Medical Advisory Council.
- On behalf of a multidisciplinary project team, **Morhardt** and **Lucca** presented at the Gerontological Society of America 2023 Annual Scientific Meeting in November 2023 in Tampa, FL.
- **Marsel Mesulam, MD**, delivered a presentation for the Harvard Medical School Brigham and Women's Department of Psychiatry Grand Rounds in November 2023.

### INTERNATIONAL

- **Elena Barbieri, PhD**, delivered an invited talk at Science of Aphasia in Nice, France in September 2023.
- **Barbieri, Lauren Ables-Torres, Sandra Weintraub, PhD**, and **Marsel Mesulam, MD**, presented their work at the Academy of Aphasia 61st Annual Meeting in Reading, United Kingdom in October 2023.

## Grants

Mesulam Center investigators received over \$4.7 million major grants that advance the field of Alzheimer's disease and related dementias. Notably, the Center received grant funding to support efforts of diversifying research participation and to study the neurophysical effects of music on individuals with Alzheimer's disease.

## 15 NEW GRANTS SEPTEMBER 2023 – AUGUST 2024

**Borna Bonakdarpour, MD, FAAN**: Characterize neuronal and glial cell-specific vulnerability to proteinopathies in Alzheimer's disease using multimodal single-nuclei genomic and epigenomic approaches (National Institute on Aging (NIA))

**Tamar Gefen, PhD**: Clinical, Neuroanatomic, and Pathologic Signatures of FTLT-tau in Dementia Phenotypes (NIA)

**Tamar Gefen, PhD**: Pathologic Substrates of Neuropsychiatric Symptoms in Aphasic Dementia (NIA)

**Tamar Gefen, PhD**: Anatomic Selectivity of Neuronal Tau in Primary Progressive Aphasia (CurePSP, Inc.)

**Changiz Geula, PhD**: Concordance of TDP-43 Inclusions with Cortical Atrophy and Clinical Phenotype (National Institute of Neurological Disorders and Stroke (NINDS))

**Changiz Geula, PhD**: Hippocampal Neurogenesis in Cognitive Function and Dysfunction in Alzheimer's Disease (NIA)

**Ian Grant, MD**: Early Onset AD Consortium – the LEAD Study (LEADS) (NIA)

**Ian Grant, MD**: ARTFL LEFFTDS Longitudinal Frontotemporal Lobar Degeneration (ALLFTD) (NIA)

**Ian Grant, MD**: Prot # A Phase 2A Randomized Double-Blind Placebo-Controlled Trial to Evaluate the Efficacy and Safety of Varoglutamstat (PQ912) in Patients with Early Alzheimer's Disease with a Stage Gate to Phase 2B (VIVA-MIND) (NIA)

**Ian Grant, MD**: AHEAD Plasma Extension (APEX) (Brigham and Women's Hospital)

**Ian Grant, MD**: ARTFL LEFFTDS Longitudinal Frontotemporal Lobar Degeneration (ALLFTD) (NIA)

**Marsel Mesulam, MD**: Asymmetric Neurodegeneration and Language In Primary Progressive Aphasia (NIA)

**Darby Morhardt, PhD, LCSW**: Geriatrics Workforce Enhancement Program: Collaborative Action Team Training for Community Health – Older adult Network (CATCH-ON) (Health Resources and Services Administration (HRSA))

**Robert Vassar, PhD**: National Alzheimer's Coordinating Center (NACC) (NIA)

**Robert Vassar, PhD**: Northwestern Alzheimer's Disease Research Center (NIA)

## Stay up to Date

Follow us on your social media channels to have the latest updates on Alzheimer's disease and related dementia research at your fingertips. We also share the human stories of people behind the research, testimonials from our research participants, and invitations to our unique educational events and conferences. Check us out!

[f facebook.com/NUMesulamCenter](https://www.facebook.com/NUMesulamCenter)

[X.com/NUMesulamCenter](https://www.x.com/NUMesulamCenter)

## Mesulam Center Editorial Committee

Mesulam Center News is published annually for research participants and friends of the Mesulam Center.

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## The Growth of the Mesulam Center Needs Your Support

Consider making a gift to support the future of dementia care and research. Each gift makes a difference.

To learn more, visit  
[brain.northwestern.edu/give](http://brain.northwestern.edu/give)



*Clockwise from Left: Tamar Gefen, PhD, reviews brain imaging with PhD students Allegra Kawles and Antonia Zouridakis.*

