

NORTHWESTERN UNIVERSITY FEINBERG SCHOOL OF MEDICINE

# Mesulam Center **NEWS**

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

FALL 2021

## **Buddy Program Thrives During a Unique Year**



## MESULAM CENTER FOR COGNITIVE NEUROLOGY AND ALZHEIMER'S DISEASE

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The Mesulam Center Advisory Board was formed to increase public awareness and knowledge of the center, and to help garner ongoing philanthropic support for the center's programs and facilities. The Board helps promote the center both locally and nationally, and assists in securing the funding necessary to position the center among the premier Alzheimer's research and patient care facilities in the United States.

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On the cover: Sareen and Jim were paired together in the Buddy Program during the 2020-21 academic year.



### DEAR FRIENDS AND COLLEAGUES:

What a year it has been! Since the publication of our 2020 newsletter, we witnessed the impressive rollout of COVID-19 vaccines, the controversial FDA approval of a new Alzheimer drug, the construction of our beautiful new Neurobehavior Clinic, the refunding of our Alzheimer's Disease P30 Research Center, and the establishment of an international consortium on SuperAging to be directed by our center.

Just a few weeks ago, the brand new Neurobehavior Clinic of the Mesulam Center opened its doors on the 13th floor of the Arkes Pavilion. It substantially increases our space and provides an uplifting environment for our patients and families. The first clinic dedicated to neurobehavioral disorders at the Feinberg School of Medicine and Northwestern Memorial Hospital was established in 1994. During the 27 years since then, the clinic has served tens of thousands of patients and has earned an international reputation for excellence in integrative patient care, innovative research, and multidisciplinary training. The new clinic will fuel further progress in all areas of activity related to our core missions.

It had been 18 years since the Food and Drug Administration (FDA) had last approved a new drug for treating Alzheimer's disease. This dry spell was broken on June 7, 2021 through the approval of aducanumab, also known by the brand name of Aduhelm. Surprisingly, however, the announcement was not greeted with the expected fanfare. In fact, the Scientific Advisory Panel of the FDA had advised against approval, three members of the panel resigned in reaction to the decision, the FDA acting commissioner launched an investigation into the process of the approval, and several major healthcare systems, including Northwestern Medicine, have declined to place Aduhelm on the regular formulary.

The factors underlying this unusual course of events are complex. To be sure, there is overwhelming evidence that Aduhelm clears the brain of amyloid, a substance that accumulates in Alzheimer's disease. However, there is no definitive evidence that Aduhelm is clinically beneficial. You can read more on the drug within these pages, and it is important to remember that there are dozens of promising clinical trials, including those conducted at the Mesulam Center, where alternative promising drugs targeting disease factors such as amyloid, tau, neuroinflammation, oxidative stress, and neurotransmitters are being developed and tested. We are working very hard within our center and also in collaboration with colleagues around the world to identify drugs that will win approval based on proven clinical efficacy.

Research is the lifeline of the Mesulam Center. It allows us to offer the most advanced diagnostic and therapeutic tools. It also allows us to explore the biological foundations of neurodegenerative diseases and the organization of neural networks that underlie memory and language. I am delighted to report that we have enjoyed a landmark year for research. Productivity in our clinical and basic research laboratories has soared, as you can see from the titles of selected publications listed in this newsletter. We have also had two major achievements in research funding. First, the Alzheimer's disease P30 Research Center that was established in 1996 has received funding for its sixth, five-year cycle, assuring that it will be continuously active for at least 30 years. Second, we were selected, through a competitive application, to establish an international SuperAging consortium that will extend research on the behavioral and biologic factors that enable unusually successful brain aging. The combined new research funding that our center attracted during the past year exceeds \$35 million.

These are some of the most consequential developments that occurred in 2021. All of us at the Mesulam Center look forward to 2022, hoping that it will be just as exciting in some ways but also more sedate in others. I always enjoy hearing from you. Feel free to contact me or any of my colleagues with comments or questions. Stay well and stay safe.

#### M. Marsel Mesulam, MD

Mesulam Center for Cognitive Neurology and Alzheimer's Disease director  
and Ruth Dunbar Davee Professor of Neuroscience

# Mesulam Center Receives \$20 Million Grant to Expand SuperAger Program Internationally

**T**he Mesulam Center was awarded a \$20 million grant from the National Institute on Aging (NIA) to establish an international multi-center SuperAging consortium. This grant, awarded in September 2021, will expand SuperAging research to locations across the United States and in Canada.

Since 2008, Emily Rogalski, PhD, associate director of the Mesulam Center, and Changiz Geula, PhD, research professor at the Mesulam Center, have studied SuperAging. Rogalski defined a "SuperAger" as someone who is over age 80 with superior memory capacity.

The consortium will expand this research and enroll 500 participants across four research sites in the United States, located in Illinois, Wisconsin, Michigan, and Georgia, as well as at a Canadian research site in southwest Ontario. The sites will focus on enrolling SuperAgers from diverse backgrounds as well as cognitively healthy individuals with similar demographics.

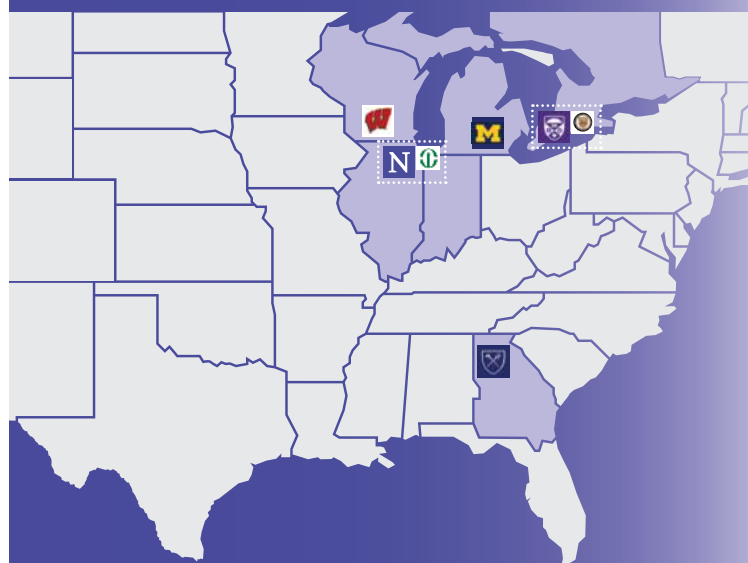
"I expect the expanded project to generate exciting discoveries on factors that enhance the brain's resistance to Alzheimer's disease and to the wear and tear of aging," said Marsel Mesulam, MD, director of the Mesulam Center.

Studying SuperAging has become increasingly important as scientists search for protective factors that enhance the brain's resilience and resistance to Alzheimer's disease.

"We are thrilled to have the opportunity to expand the study of SuperAgers who are teaching us about protective factors associated with aging," Rogalski said. "Their stories and biology are providing an opportunity to redefine expectations and reduce stigma associated with aging."

Some of the key findings show SuperAgers have brains that look 20 to 30 years younger than their peers and resist cortical shrinkage. Their brains also have higher levels of Von Economo neurons, which are thought to be important for communication. Additionally, scientists have learned SuperAgers have resistance to the development of fibrous tangles in a brain region related to memory, tangles that are known to be markers of Alzheimer's disease.

## RECRUITMENT AND REFERRAL SITES



**Primary recruitment sites include University of Michigan, University of Wisconsin, Emory University, Western University, and Northwestern University. Rush University and University of Waterloo will provide key referrals.**

Expanding efforts throughout North America will aid in isolating factors that promote successful cognitive aging, Rogalski said, and perhaps prevent age-related brain diseases such as Alzheimer's disease.

The project, "Study to Uncover Pathways to Exceptional Cognitive Resilience in Aging," is supported by NIA grant 1U19AG073153-01 from the National Institutes of Health.

"I expect the expanded project to generate exciting discoveries on factors that enhance the brain's resistance to Alzheimer's disease and to the wear and tear of aging."

M. MARSEL MESULAM, MD

# Faculty Provide Expertise Locally, Nationally and Globally

Even in a unique year of remote work and virtual conferences, Mesulam Center faculty continue to serve in a variety of leadership roles in the city of Chicago, nationally, and even abroad.

## Local

- Borna Bonakdarpour, MD, is now the director of the Northwestern Music and Medicine program in collaboration with Clara Takarabe, Chicago Symphony Orchestra's violist and music practitioner.
- Bonakdarpour also received a certificate of appreciation for completing a Recuperation Room project in collaboration with Northwestern Medicine Wellbeing team, which offers a place for physicians to relax and reset.
- Darby Morhardt, PhD, LCSW, was named a member of the Alzheimer's Association's Illinois Chapter Diversity, Equity and Inclusion Committee.
- Tamar Gefen, PhD, presented the keynote at the Northwestern University Brain Awareness Outreach (NUBAO) annual Teachers' Workshop that showed a new way to teach elementary and middle school students about neurodegenerative diseases.
- Maureen Daly, PhD, presented, "Brain Health Basics: Lifestyle and Living Skills to Promote Wellness" at a community event in collaboration with The Atlas Senior Center in February 2021.

## STAFF ACCOMPLISHMENTS

In addition to the extraordinary efforts of the faculty, this year four Mesulam Center staff members were recognized for their contributions to the Feinberg School of Medicine with prestigious Feinberg Service Excellence Awards.

The recipients include:

- Edwin Morales, Financial Assistant
- Leela Rao, Clinical Research Associate
- Michaela Riley, Research Project Manager
- Callen Spencer, Senior Research Technologist

## National

- Sandra Weintraub, PhD, professor of Psychiatry and Behavioral Sciences, presented Courageous Conversations hosted by the UsAgainstAlzheimer's in April 2021.
- Weintraub was recognized by the National Institute on Aging for her considerable time and effort in developing the Uniform Data Set version 4 as a member of the Alzheimer Disease Research Center (ADRC) Clinical Taskforce.
- Emily Rogalski, PhD, served as an elected member of the Imaging Steering Committee for the National Institutes of Health and National Institutes on Aging Alzheimer's Disease Research Centers program.
- Darby Morhardt, PhD, LCSW, served as subject matter expert and hub faculty member for the Alzheimer's Association's Alzheimer's and Dementia Care Project ECHO (Extension for Community Healthcare Outcomes) Telehealth series.

## International

- Rogalski served as an elected executive committee member and site selection chair, International Society for Frontotemporal Dementia, which hosted its Virtual Congress for the International Society for Frontotemporal Dementias, in March 2021.
- Morhardt was named to the International Society to Advance Alzheimer's Research and Treatment (ISTAART) Frontotemporal Dementia (FTD) Diversity and Disparities Professional Interest Area (PIA) Subgroup.
- Morhardt is also working on a virtual exchange with Shanghai Chicago Sister Cities International – Social Services with Older Adults about dementia care practices.

# A Personal Connection: On Becoming a Neuropathologist and Scientist

**M**argaret Flanagan, MD, learned firsthand about the effects of dementia when her father developed the disease while she was in medical school at Trinity College Dublin.

She then discovered the rewarding field of neuropathology while completing a clerkship at the Mayo Clinic in 2012. In 2017, Flanagan's mother also lost significant memory function, and Flanagan became her primary caregiver.

Because of these personal experiences, Flanagan has committed her life's work to better understanding dementia. She currently serves as Neuropathology Core Leader at the Northwestern Alzheimer's Disease Research Center and is an assistant professor of Experimental Pathology and Neuropathology with her own research program.

"I love my job because I can work on making important breakthroughs in neuropathology to help people like my parents," Flanagan said. "The most important part is to make the quality of life better for those who are currently living with dementia."

Part of Flanagan's role is to meet with the families of our research participants who donated their brain at the time of death, where she discusses the results of the brain autopsy. In these meetings, Flanagan often shares stories about her own personal experience caring for her parents with dementia, which helps to create a safe and comfortable space for the families.

"It's often a celebration of life, too," she said. "We talk about the life that person lived. But the brain autopsy also provides the pathological answers to the disease, which many families take comfort in knowing."

After caring for her father and currently taking care of her mother, Flanagan's career goal is to identify effective treatments that will help other families living with dementia.

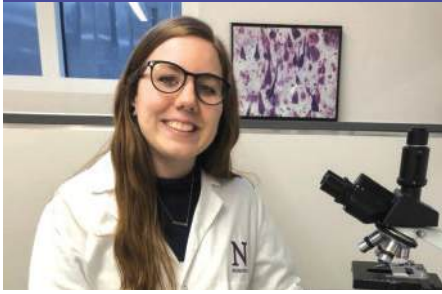
"I like that my career provides me with two opportunities: taking care of patients and working to help the future of dementia research by searching for disease markers that will ultimately help discover later treatments," she said.



Margaret Flanagan oversees a neuropathology lab located in the Mesulam Center.

"We talk about the life that person lived. But the brain autopsy also provides the pathological answers to the disease, which many families take comfort in knowing."

MARGARET FLANAGAN, MD



## Staff Member Profile: Callen Spencer

**C**allen Spencer has worked at the Mesulam Center for three years and was recently promoted to senior research technologist.

"I feel super fortunate to have the mentors that I have at the Mesulam Center and the people in my life who are giving me all these opportunities that I never imagined I would have," she said.

Spencer started at the Mesulam Center in March 2018, after graduating from University of Illinois Chicago with a BS in biology and a minor in anthropology. She knew that medical school was not the path for her and instead wanted to pursue her passions in pathology, forensics, and lab work.

As a senior research technologist, Spencer is responsible for handling brain autopsies in the lab of Margaret Flanagan, MD, assistant professor of Pathology. This includes brain cutting, photographing, tissue staining, and preservation of the brain tissue.

"I like that I get to help determine what happened to someone's loved one and that I get to give them some piece of mind," Spencer said. **"Being involved in the process of explaining the pathology to someone is really important. Alzheimer's and other causes of**

**dementia are terrible diseases, so any information we can gather on the disease pathology is a step in the right direction."**

In addition to her work in the lab, she also is the captain of the center's Walk to End Alzheimer's team. The event brings the Mesulam Center community together to support each other and raise funds for dementia research and support.



## New Faculty Profile: Joshua Cahan, MD

**G**rowing up, Joshua Cahan, MD, always knew that he wanted to be a doctor. As a child, he was inspired by his father's work as a gastroenterologist. Living his dream, Cahan has worked as a fellow at the Mesulam Center for the last two years and became assistant professor of Neurology at the Mesulam Center in summer 2021. He also serves as a neurologist in the Neurobehavior and Memory Clinic.

Before medical school, Cahan studied music and computer science at New York University. As a music major, he focused on jazz, bossa nova guitar, and ethnomusicology. It was there that he



began to read books about the brain and became fascinated with neurology.

**"Neurology feels like a puzzle,"**

he said. **"First, you must understand the anatomy of the brain, and then you figure out what can go wrong in the pathology."** He switched his focus to medicine, attending Chicago Medical School at Rosalind Franklin University.

At the Mesulam Center, Cahan's clinical focus is in behavioral neurology. During his fellowship, his research involved using biomarkers to look into the behavioral and psychological symptoms of dementia (known in the field as the acronym BPSD). Recently, Cahan's research into anti-psychotics and

BPSD suggests a relationship between lower cerebrospinal fluid (CSF) levels and earlier anti-psychotic use in dementia patients. Additionally, Cahan has been conducting research on the long-term effects of "brain fog" in COVID-19 patients.

"I am looking forward to establishing myself as an expert in dementia, carving a path as a researcher, and working and collaborating with great colleagues," he said.

Perhaps Cahan will inspire his own children to become physicians. His first child, daughter Maya Goldie, was born in January 2021.

# Meeting Growing Needs: Expanding the Clinic

## CENTER BUILDS MORE SPACE FOR PATIENTS AND CAREGIVERS TO MEET WITH CLINICIANS AND STAFF

**A**s the need for dementia care and research grows, so has the Mesulam Center and its clinical practice — the Neurobehavior and Memory Clinic. To meet this demand, the Center has renovated a new clinic — double the size of the old clinic — that will provide more space for patients, clinicians, staff, and their families to come together to discuss care and improve quality of life for patients.

“Everything that we do in the clinic benefits research and vice versa,” said Marsel Mesulam, MD, director of the center. “A larger clinic will allow us to see more patients and bring together our clinicians from across disciplines, including social work, behavioral neurology, neuropsychology, and neuropathology.”

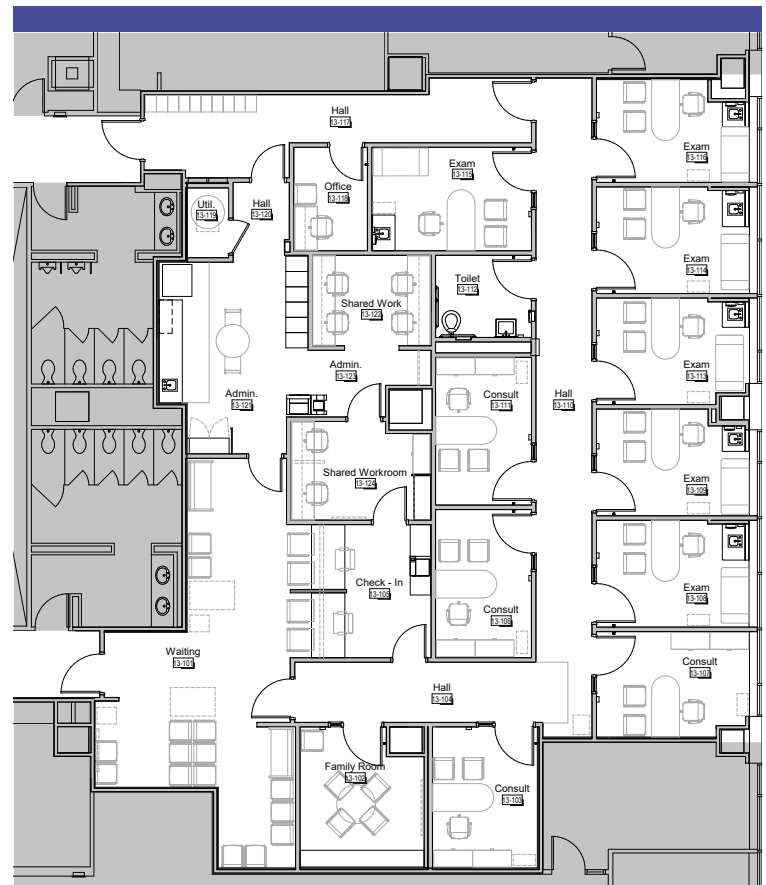
Mesulam has been involved with four clinical and research space re-designs in the last 27 years. The last renovation took place in 2018, when generous donors supported a new research space on the eighth floor of the Tarry Building. The new office layout supported the integrated work of a nationally funded Alzheimer’s Disease Research Center through collaborative offices and laboratories. It was then that the center — formerly known as the Cognitive Neurology and Alzheimer’s Disease Center (CNADC) — was renamed for Mesulam.

### More convenient for patients

The new clinic remains rooted in the mission of the center to better understand diseases of the brain and bring that information directly to those living with those diseases. Knowledge gained on Tarry 8 benefits the patients in Arkes Pavilion, and vice versa.

“We need to continue to investigate how the brain works and why the brain sometimes fails to work, and use this knowledge to benefit our patients and families,” Mesulam said.

Sandra Weintraub, PhD, noted that the additional space will also make it more convenient for individuals who are also enrolled in research to have a research visit in the same place as their clinical visit for medical care.



The new Neurobehavior Clinic of the Mesulam Center opened its doors in October on the 13th floor of the Arkes Pavilion.

### A calming space

The new clinic was intentionally designed, from the paint colors to the art, to be a calming place. For many, a dementia diagnosis can be difficult to process. “We want to create a setting that is welcoming and soothes anxiety,” Mesulam said.

Several consult rooms in the new clinic are designed with video capability, so students, residents, and fellows can view and learn from clinical sessions without overcrowding the room, a result of the adaptations made during the pandemic.

**The growth of the Mesulam Center needs your support. Consider making a gift to support the future of dementia care and research. To learn more about giving, visit [brain.northwestern.org/give](https://brain.northwestern.org/give).**

# NEW MESULAM CENTER FELLOWS

## Allison Lapins, MD

FLORANE AND JEROME ROSENSTONE  
BEHAVIORAL NEUROLOGY FELLOW



After spending the past eight years completing medical school and residency, Allison Lapins, MD, is excited to return to clinical research at the Mesulam Center as one of our new Florane and Jerome Rosenstone Behavioral Neurology Fellows.

"I find clinical work to be rewarding and meaningful because you are treating patients and helping their families at the same time," Lapins said.

Lapins completed her undergraduate degree in neuroscience at the University of Miami in Florida. Following graduation in 2013, Lapins attended Rosalind Franklin Medical School in Chicago and worked her intern year in internal medicine at Northshore University HealthSystem. In 2021, she completed her neurology residency at University of Chicago, and also completed a one-year fellowship on medical ethics.

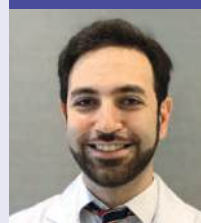
Lapins said she has always had an interest in the brain and neuroscience. As an undergraduate, Lapins worked as a research assistant at the Miller School of Medicine, investigating neuronal regeneration. This experience helped strengthen her research interest in neurodegenerative diseases. Her interest turned into a serious passion for neurodegenerative diseases after her grandfather was diagnosed with dementia.

For her fellow project, Lapins hopes to conduct research in the correlation between cognitive function and anatomy.

**"Not only am I looking forward to working alongside these amazing clinicians at the Mesulam Center, I am also excited to work in an interdisciplinary community,"** Lapins said. "It's rare in this field to be surrounded by clinicians, pathologists, and social workers. It helps to see all the aspects of a patient's journey."

## Malik Nassan, MD

FLORANE AND JEROME ROSENSTONE  
BEHAVIORAL NEUROLOGY FELLOW



Malik Nassan, MD, applied to the Florane and Jerome Rosenstone Behavioral Neurology Fellowship because he wanted to learn cognitive neuroscience and cognitive neurology from center director Marsel Mesulam, MD, whom he referred

to as "the modern father of the field."

Nassan grew up and went to medical school in Saudi Arabia. He was awarded a full-merit scholarship to Al-Faisal University and King Faisal Specialist Hospital and Research Center. After graduating in 2014, Nassan took many opportunities to dive into research in genetics, neuroscience, and neuropsychiatric diseases.

For his residency, Nassan went to the Mayo Clinic in Rochester, Minnesota. There, he worked on neuropsychiatric genetic research, the study of genetic research in the brain and as it relates to psychiatric disorders. He completed a postdoctoral research fellowship at the Mayo Clinic, investigating the molecular underpinnings in bipolar disorder to help treatment findings. Before coming to the Mesulam Center, Nassan spent a year at Harvard Medical School in a clinical fellowship that focused on sleep medicine. Additionally, Nassan has been first author on articles related to neuropsychiatry genetics.

**"I believe we are still at the infancy stage of understanding how the human brain works, which limits patient care,"**

Nassan said. "I hope to work in the field of neurodegenerative disorders and use my background in genetics, neuroscience, and sleep medicine to develop better treatments for our patients."

Nassan is passionate about translational research because he wants to improve patient care as much as possible. He is looking forward to starting a research path that leads to him being a scientist physician supported by NIH grants to run his lab in the future.

"Learning from Dr. Mesulam is a wonderful opportunity," Nassan said. "I aspire to have knowledge like him one day: a strong base knowledge about brain networks, neurology, and clinical training to give the best care and treatment to my patients and do cutting edge research to advance the field."

## Kate Maley, MSW

GLEN AND WENDY MILLER FAMILY  
SOCIAL WORK FELLOW



Each year, the Mesulam Center offers a unique opportunity for a social worker to develop clinical skills while working with individuals living with dementia and their families through the Glen and Wendy Miller Post Graduate Social Work Fellowship in Neurocognitive Disorders.

This year's fellow is Kate Maley, MSW. Maley studied anthropology at Rutgers University, then completed her first master's degree in medical anthropology at the University of Chicago. Inspired by her interests in humanity and healthcare, she was drawn to seek a second master's degree in social work while working at Shriver Center on Poverty Law in Chicago.

Maley recently finished that degree at the University of Illinois Chicago and started at the center in August 2021. As a fellow, she will gain experience working in the Neurobehavior and Memory Clinic and will also conduct academic research.

**"With social work, I can keep that broader perspective by focusing on equity and justice,"** Maley said. "It also gives me the skills to work with people on mental health and other direct, immediate needs."

Before coming to the Mesulam Center, Maley contributed to various research projects and policy initiatives. At the University of Iowa, she worked on post-treatment outcome research at substance abuse facilities. At the University of Chicago, she worked on a program that helped medical providers address the social determinants of health by building a community resource database. Most recently, at the Shriver Center on Poverty Law, she worked primarily on Medicaid issues and expanding access to dental care through legislative and policy channels.

Maley is excited to be a part of the Mesulam Center's integrated community that is working to support individuals living with dementia and their families.

"I'm really excited about the blend the Mesulam Center provides: direct care, research, clinical trials, and qualitative work," Maley said. "Working in such an interdisciplinary environment is really important for the direction that health care needs to be going."

## CENTER STAFF AND FACULTY PRESENT RESEARCH VIRTUALLY

### INVESTIGATORS ARE STILL UNDERTAKING CRITICAL RESEARCH DURING THE PANDEMIC

**T**hroughout the pandemic, not only has the Mesulam Center hosted their own online conferences, center staff and faculty have also presented at virtual conferences around the world.

Allegra Kawles, a research technologist and laboratory manager for the lab of Tamar Gefen, PhD, presented at the Society for Neuroscience Conference (SfN) in January 2021 and at the International Neuropsychological Society (INS) in February.



Allegra Kawles presented virtually at the SfN conference.

At the SfN conference, Kawles presented on the pathologic correlates of neurodegeneration in a rare neurodegenerative disease, the C subtype of frontotemporal lobar degeneration with TDP-43 inclusions (FTLD-TDP-type C). Additionally, Kawles received the 2020 Trainee Professional Development Award from SfN.

Continuing to present research at virtual conferences is important for both the Mesulam Center and the Alzheimer's disease and related dementias (ADRD) community as a whole.

"By continuing to present and share our research, we are able to let our scientific and patient communities know that critical research to find new and better treatments is still happening," said Darby Morhardt, PhD, LCSW, research professor at the Mesulam Center.

In July, center faculty and staff presented their work at the hybrid Alzheimer's Association conference, including Robert Vassar, PhD, on BACE inhibitors for Alzheimer's, and Sandra Weintraub, PhD, on the Dementia Nomenclature Initiative, a three-year national initiative to explore opportunities to improve communication about cognitive impairment, dementia, and the diseases that cause them.

**See a video recap from AAIC at**  
[brain.northwestern.edu/connections](https://brain.northwestern.edu/connections).

# Pilot Grants Support Innovative Dementia Research

## PILOT GRANTS HAVE LAUNCHED AND SUPPORTED EARLY CAREERS IN THE FIELD OF ALZHEIMER'S RESEARCH FOR 24 YEARS.

**W**ith funds from the National Institutes of Health (NIH), the Mesulam Center provides two \$35,000 grants to investigators to generate early-stage research data that can be used for larger funding applications down the road. The two recipients have typically included one clinically oriented project and one basic science investigation to further understand dementia.

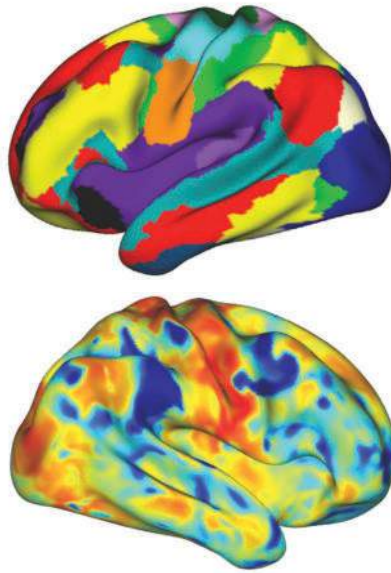
### PRECISION fMRI SCANNING IN OLDER ADULTS

**Caterina Gratton, PhD**

The first of the two awards went to Caterina Gratton, assistant professor of Psychology, for her work in functional magnetic resonance imaging (fMRI) scanning in older adults. The initial idea of the research was to examine how brain function and brain activity interactions change over time. Gratton and graduate student Diana Perez were seeking to find how control networks — responsible for guiding “goal-directed” activities — function in the brain and human brain networks, and to understand the variation of brain networks across the human lifespan.

To measure brain networks, the investigators used fMRI to measure the relationships across brain regions over time, called functional connectivity.

The typical approach for mapping brain networks is to take small amounts of data — about five to 10 minutes of fMRI scans per subject — and pool the data together to create a group average. While this can produce robust brain networks of the group average, it does not provide a picture of each individual subject's brain activity. However, in Gratton's lab, the investigators helped develop



Top is a picture of typical brain networks, and below is a picture of locations of individual variation.

a precision fMRI (pfMRI) approach through extensive scanning of each individual. The individual imaging over multiple sessions leads to more reliable and stable measures about an individual's brain activity. Using pfMRI, the lab was able to compare the brain networks to identify what effects aging has on executive brain functions.

Next steps for the lab include collecting more pfMRI participants to characterize individual differences in brain organization in older adults and determining the relationship of brain organization to behavioral changes.

“We benefit so much from research participants at the Mesulam Center,” Gratton said. “We are hopeful that by hearing about our work, participants will be enthusiastic and feel like they are contributing to really important and interesting scientific questions.”

**If you are interested in participating in the Gratton Lab, contact Caterina Gratton at [cgratton@northwestern.edu](mailto:cgratton@northwestern.edu).**

### BASAL FOREBRAIN CHOLINERGIC NEURONS IN AGING AND PROTEINOPATHIES

**Tristano Pancani, PhD**

The second pilot grant was awarded to Tristano Pancani, research assistant professor of Physiology, who is working with James Surmeier, PhD, the Nathan Smith Davis Professor of Physiology. Pancani's research explores why certain neurons — called the basal forebrain cholinergic neurons — are more susceptible to aging, Alzheimer's disease, and related dementias. The neurons are specialized to transmit acetylcholine, which plays a role in many cognitive functions including short term memory.

“My approach is to always look at the physiology before the pathology,” Pancani said. “If you figure out how the neuron works — or doesn't work — then you can figure out what can go wrong in different diseases and then find various treatments.”

Even though cholinergic neurons are a small population of cells in the basal forebrain, they have long, extended axons that travel all over the cortex — making them responsible for much of the cortex plasticity, the brain's ability to make new neural connections. Loss of these neurons is a hallmark of dementias and is the reason why cognitive and attentional deficits are seen in Alzheimer's disease and other related dementias.

Pancani is attempting to find why and how these neurons are so vulnerable in aging and dementias.

These neurons are also sensitive to insulin; Pancani and his team examined how insulin activity is affected with age and Alzheimer's disease to understand how that correlates with the activity of cholinergic neurons.

# Renewing a Commitment to Dementia Research

The National Institute on Aging (NIA) has renewed the Alzheimer's Disease Research Center (ADRC) P30 grant, housed in the Mesulam Center, for another five years of funding.

The ADRC P30 was established with NIA funding in 1996 and directed for 25 years by Marsel Mesulam, MD. The current P30 principal investigator is Robert Vassar, PhD.

Receiving the P30 grant distinguishes the Mesulam Center as one of a group of 33 ADRCs at major medical institutions across the United States. These research institutions serve as major sources of discovery into the nature of Alzheimer's disease and related causes of dementia, as well as the development of more effective approaches to prevention, diagnosis, care, and treatment.

The nationwide network of ADRCs contribute significantly to the development of shared resources that support dementia-relevant research, and they collaborate and coordinate their research efforts with other National Institutes of Health (NIH)-funded programs.

The competitive grant renewal process ensures that each ADRC continues to meet NIH standards and goals and shows innovative scientific contributions. The P30 grant is important to the financial infrastructure of the Mesulam Center and for the recruitment of individuals who are cognitively healthy or have early stages of cognitive impairment or who are living with a diagnosis of dementia into our research studies. The ADRC funds the core teams, labs, and data collection efforts, contributing to the National Alzheimer Coordinating Center (NACC), a national database.

This year's application by the Mesulam Center proposes a plan to unify around the theme: "Heterogeneity in Aging and Dementia: Pathways to Intervention and Discovery." The concept of "heterogeneity" was introduced at the Mesulam Center more than 25 years ago and acknowledges the large range of cognitive aging pathways an individual could take, from those who experience cognitive decline to SuperAgers. Each experience lands along a spectrum of aging trajectories, and the center follows individuals across the spectrum.



Robert Vassar, PhD, and Sandra Weintraub, PhD, are co-principal investigators on the P30 grant.

Heterogeneity also refers to individual differences in dementia symptom expression that require different nonpharmacologic interventions for affected individuals and their support networks. For example, while some individuals have memory loss, others retain memory but experience language loss. Yet others may have neither early memory loss nor language difficulties, but instead experience uncharacteristic personality changes. These differences are of biological importance, and research that originated at the Mesulam Center has also shown that dementia care needs to be tailored to the individual and is not a matter of "one size fits all."

## STAY CONNECTED

This year the Mesulam Center received several new national grants, in addition to new grants like the SuperAging grant from the National Institute on Aging (NIA). You can stay up to date with the latest news by subscribing to our email newsletter at [brain.northwestern.edu/connections](mailto:brain.northwestern.edu/connections).

# Online Conferences Offer Connections During the Pandemic

**W**hen the COVID-19 pandemic began in 2020, the Mesulam Center had to smoothly transition to hosting two conferences online. While not being able to gather in person was disappointing, the virtual conference format allowed the Mesulam Center to reach more people from across the country and around the world.

## Finding support for a rare diagnosis

The Primary Progressive Aphasia (PPA) conference: Communication and Connection 2021 was held online in March. Originally scheduled for March 2020, the event had to be postponed due to the pandemic. Emily Rogalski, PhD, associate director of the Mesulam Center, said because the conference plays an important role in building connections for persons and families living with PPA, center staff decided to host the conference online.

"With such an uncommon diagnosis, it's difficult for people with PPA to meet others living with PPA," said Rogalski, who is also a professor of Psychiatry and Behavioral Sciences. "We know that we can help form those connections, and they are so valuable to individuals with PPA and their families."

The virtual format of the conference, held over Zoom, attracted 360 attendees from 15 different countries. Throughout the day, the conference offered a keynote address about the current state of research for PPA, a Q&A panel with persons living with PPA and their families, and separate support groups for individuals with PPA and their care partners.

"Through support groups and by sharing their lived experiences, persons with PPA and their families begin to feel like they're not alone," Rogalski said. "We wanted to offer hope that you can continue to live a meaningful life with PPA."

Ken and Barb Stevenson found that sense of hope and connection by attending the conference online from Canada. Ken estimates that there are fewer than 10 people in the city of Calgary, Canada living with PPA, so being able to tap into a global community through the conference was beneficial. He is the care partner for his wife, Barb, who was diagnosed with PPA two years ago. The couple attended virtually with their daughter and found it comforting to hear others' stories.

Many other attendees reported positive experiences with the conference, as well. "Thank you for the professionalism and flow of these sessions. The information was highly relevant, flowed so well,

## ATTENDEE AFFILIATIONS AT THE 27TH ALZHEIMER DAY



and really humanized the experience," one attendee wrote in an evaluation. "It was incredibly impactful for both family caregivers and professionals partnering in care."

## Offering insight into quality of life

Two months later, the center hosted its 27th Annual Alzheimer Day on May 6, the second year this event was held virtually. Marsel Mesulam, MD, director of the Mesulam Center, addressed the virtual nature of the conference in his opening remarks.

"We've done the next best thing by holding the 27th Annual Alzheimer Day virtually. And looking at the size and composition of the audience, I have every reason to be as proud today as I've been in the past," he said. The audience consisted of scientists, researchers, healthcare and social workers, individuals living with dementia, research participants, and family or friends of a person with dementia.

The conference was held for two hours in the afternoon and featured Rogalski as the Mendelson Lecturer. She discussed the center's expertise in atypical dementias, including PPA and frontotemporal dementia (FTD). She also touched on the varying ways the center seeks to optimize quality of life, including through support programs and research studies.

The second half of the conference was the Quality of Life Symposium, sponsored by the Glen and Wendy Miller Family Foundation, which featured three families living with different types of dementia, including PPA, behavioral variant frontotemporal dementia, and young-onset Alzheimer's disease dementia. Family members offered insight into what it's like to both live with dementia and care for someone with dementia during the pandemic.

**Read more about Alzheimer Day at [brain.northwestern.edu/ADay21](http://brain.northwestern.edu/ADay21).**

# A Family Affair

## MARRIED COUPLES AND FORMER PARTICIPANTS' CHILDREN WHO TAKE PART IN RESEARCH HELP INVESTIGATORS UNDERSTAND DEMENTIA

**F**or some center research participants, their involvement goes beyond working with research assistants and faculty; participating in research at the Mesulam Center is a family activity.

Miriam Kalichman is a current research participant at the Mesulam Center, and it's basically in her DNA. Both of Miriam's parents, Bette and Nathan Kalichman, participated in the SuperAging Research Program and Northwestern's Alzheimer's Disease Research Center, which is commonly referred to as the Clinical Core study and is funded by the National Institute on Aging.

In the early 2000s, Miriam's parents heard about the SuperAging Program, which follows people 80 years old and older who have the memory capacity of 50 year olds. The Kalichmans were fascinated by the research project and decided to enroll as participants. Miriam enjoyed learning about their visits and assessments at the Mesulam Center. After Miriam's mother died, Miriam became her father's study partner, which inspired her to participate in research years later. Through the example of her parents, Miriam witnessed first-hand the importance of being a research participant. She now participates as a cognitively healthy volunteer in the Clinical Core study, and she also enrolled into the Primary Progressive Aphasia (PPA) study as a cognitively healthy volunteer.

"It is important in many areas of understanding dementia and its causes to be able to study an affected individual's family," said Sandra Weintraub, PhD, director of the Clinical Core study. "This is especially true if other family members in the same generation or across generations have suffered from similar illnesses."

### Benefitting research through brain donation

Jay and Lou Ann Schachner are one of two married couples currently enrolled in the Center's SuperAging study, which makes their participation in the study quite unique. The couple started in the Clinical Core study about 20 years ago, and then joined the SuperAging study when they each turned 80 years old.

"We believe that this is important research because we know people who struggle with various dementias," Lou Ann said. "It's beneficial to society."

Another important family tradition for both the Kalichmans and the Schachners is brain donation. When Bette Kalichman participated in Mesulam Center research studies, she was adamant about donating



Miriam Kalichman and her family. From left to right, top row: Miriam, her husband, and her son. Bottom row: Miriam's father, daughter, and mother. Credit: Miriam Kalichman

her brain when she died. Even in the last days of her life, she was passionate about making sure her brain ended up in the right place. After witnessing the selflessness of his wife, Nathan Kalichman also donated his brain after passing.

When people like the Schachners and the Kalichmans donate their brains, they allow researchers to compare biological changes in their brains over time to those found in the brains of people who lived with dementia. By examining brains with and without Alzheimer's and other dementias, clinicians and scientists gain a better understanding of the diseases, and what areas of the brain diseases attack, and make progress toward finding treatments and cures.

"We don't need our brain after we pass away, so it is our contribution to medical science," Jay Schachner said.

**"It is important in many areas of understanding dementia and its causes to be able to study an individual's family."**

SANDRA WEINTRAUB, PHD

### Understanding hereditary forms of dementia

Familial participation in research is a unique and important contribution. Studying multigenerational family members can provide insight into the hereditary forms of dementia caused by both Alzheimer's disease and frontotemporal dementia.

"A family history provides the evidence for the hereditary nature by identifying multiple affected family members within and across generations," Weintraub said. "In most cases, most dementia is 'sporadic,' meaning not inherited."

**Family participation allows for richer insight into cognitive aging and how dementia affects individuals and families. If interested in participating in research, visit [brain.northwestern.edu/join](https://brain.northwestern.edu/join) to learn more.**

# A Grandfather's Legacy Lives on Through Brain Donation

By **Chloe Hilles**

**T**here are two things my grandfather will always be remembered for: his lifelong affinity for learning and his generosity towards others. In a way, these qualities transcend my grandpa's life as his wish for post-mortem brain donation was fulfilled.

My grandfather, Jay Bockserman, passed away peacefully at home surrounded by family and music in late May 2021. He had been battling Alzheimer's disease since 2012. After his passing, my responsibility as the granddaughter who works at an Alzheimer's Disease Research Center (ADRC) was to find a place to donate his brain to Alzheimer's and dementia research.

## A history of Alzheimer's disease

As a family, we had always known that my grandfather would donate his brain to scientific research — even before he was diagnosed with Alzheimer's disease.



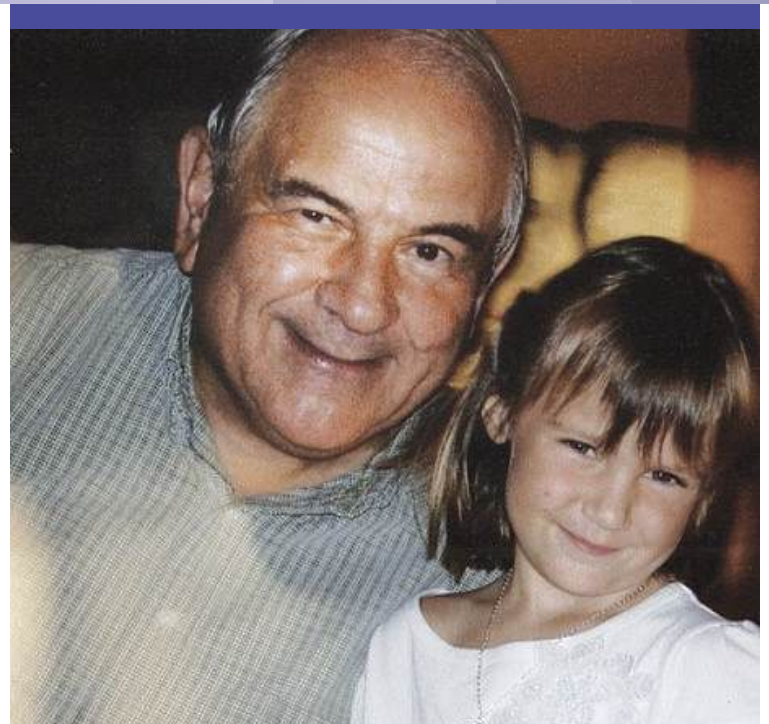
Looking at brain tissue is key to better understanding Alzheimer's disease and related dementias.

Our family has a history of Alzheimer's disease, which includes my grandfather's mother. After she passed away in 1987, my grandfather ensured that her brain was donated to an ADRC so she could contribute to the future of Alzheimer's research.

For my grandfather — a straightforward man

driven by his strong convictions — agreeing to brain donation was an easy decision; he didn't need his brain after death, and it could be used to help others, including his family. For me, his decision makes him immortal.

Even though my grandfather, with his big-bellied laugh, is no longer sitting at the head of the dinner table with his family, he is still around somewhere. He is forever advancing research and contributing to the health and wellbeing of his peers and family.



Chloe, at age 5, with her grandfather Jay Bockserman.

**"For me, his decision makes him immortal."**

**CHLOE HILLES**

"There is almost a reincarnation every single time I go into the brain bank; every time I go in, it's like I meet that person again," Tamar Gefen, PhD, told me in an interview. "They come back to life, and they come back to life in a way that's helping their peers."

## Making an impact beyond your lifetime

Brain donation is the last step for many in their journey on earth. Whether they are a person living with dementia or a cognitively healthy volunteer, many agree to brain donation. In the year 2020 alone, the Mesulam Center received brain donations from 43 persons living with dementia and cognitively healthy volunteers.

After the death of my grandfather, who did not participate in research studies while alive, we proceeded with brain donation through the Brain Donor Project. However, if you have the opportunity to get involved with a research study now, that is the most effective way to contribute to research in the field of aging and dementia prior to brain donation. We carried on my grandfather's legacy through brain donation, and I will see him and his impact in the advancements of future dementia research.

*Chloe Hilles is the content writer intern for the Mesulam Center.*



Mesulam Center Lab staff members Allegra Kawles, Jackie Lilek, Grace Minogue, and Rachel Keszycki volunteer with Northwestern University Brain Awareness Outreach.

## Educating Chicago Students about Dementia

Do you remember learning about dementia in school? It's likely it was not part of your curriculum, but Mesulam Center staff and faculty are committed to building excitement about how the brain allows us to remember, feel, think, and speak.

In March, Tamar Gefen, PhD, assistant clinical core director of the Northwestern Alzheimer's Disease Research Center, presented the keynote at the Northwestern University Brain Awareness Outreach (NUBAO) annual Teachers' Workshop that showed a new way to teach elementary and middle school students about neurodegenerative diseases.

NUBAO, a public outreach initiative founded in 2010 by Northwestern University Interdepartmental Neuroscience (NUIN) students, partners with public schools and science education programs in the Chicago area to teach a variety of neuroscience topics to students of all ages and their families.

For the spring workshop, research staff Allegra Kawles, Jaclyn Lilek, and Grace Minogue worked with Gefen to design a teaching module on neurodegeneration, which includes a PowerPoint presentation that Chicago area teachers can use in their classrooms. The module includes activities to help the students better understand what specifically goes wrong in neurodegenerative diseases that cause cognitive impairment with aging and dementia.

Lilek noted that early exposure to topics like neuroscience can spark an interest in science that could encourage new career paths and interests. "It is important for students of all backgrounds to have the opportunity to learn about various STEM topics, like neuroscience," she said. "Personally, I would never have taken an interest in neuroscience or even health sciences in general if I had not been exposed to them through family members and specialized topics in school."

As a member of a world-renowned center for dementia, Minogue said it's important to spread knowledge in the community. "We have a lot of power here, and it's important for us to remember to take a step back from academia and teach what we know to the community," she said.

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**The module is available online at [brain.northwestern.edu/NUBAO](https://brain.northwestern.edu/NUBAO).**

# Understanding the New Alzheimer's Drug Aducanumab

## THE DRUG WAS APPROVED IN JUNE, BUT CENTER PHYSICIANS QUESTION THE EFFICACY

In June 2021, the FDA approved the first new drug in 18 years to treat Alzheimer's disease. The drug, called aducanumab and marketed as Aduhelm by Biogen, removes amyloid from the brain.

The decision was controversial because the drug was approved through an accelerated approval process and hasn't been proven to change an individual's symptoms of Alzheimer's disease.

The approval of aducanumab resulted from two clinical trials, the first of which showed no clinical impact. While the second trial showed similar results, Biogen then accessed and submitted additional information showing that the second trial had reduced progression of the disease by 22% in comparison to the placebo.

Though the FDA Advisory Committee did not recommend approval based on this evidence, the FDA approved the medication on June 7, 2021 for the treatment of Alzheimer's disease based on the idea that removal of the plaque from the brain should theoretically slow progression, even if this has not yet been proven with the rigor usually required in clinical trials.

In June 2021, the FDA approved the first new drug in 18 years to treat Alzheimer's disease. The drug, called aducanumab and marketed as Aduhelm by Biogen, removes amyloid from the brain.

### Eligibility, administration, and side effects

To be eligible for Aduhelm, individuals must have progressive weakness of memory or thinking that is mild, as determined by quantitative testing. Secondly, they must undergo a spinal tap or PET scan to show that they have amyloid in the brain. Aduhelm has not been studied in moderate or advanced disease.

The drug is administered by monthly intravenous infusions that each last about one hour. Side effects may include brain swelling and pinpoint areas of blood seepage into the brain. These brain abnormalities are usually asymptomatic. Occasionally, the drug-related brain abnormalities will cause symptoms. The most common



The FDA approval of Aduhelm has been controversial and health insurance coverage is still pending.

are headache, dizziness, or confusion. To monitor these potentially dangerous side effects, the patient will need to have brain scans before the seventh infusion and the twelfth infusion, if significant symptoms arise. The related symptoms are expected to be temporary.

### Information, availability, and recommendations from the center

The Mesulam Center and Neurobehavior and Memory Clinic hosted an online community forum in August for affected individuals to hear directly from Marsel Mesulam, MD, and Ian Grant, MD, about aducanumab. More than 160 registered for the community forum, and attendees were able to ask questions through a Q&A session.

At Northwestern Medicine, Aduhelm is not available as of October 2021, due to unknown Medicare and health insurance coverage. It is estimated the drug could cost \$56,000 or more per year if paid out of pocket.

Until there is better proof that it has a beneficial clinical effect, the Mesulam Center and Neurobehavior and Memory Clinic physicians have reservations about the use of Aduhelm. However, they will not rule it out either. More information will be shared with the Mesulam Center community and patients of the Neurobehavior and Memory Clinic as it becomes available.

## 2021 RESEARCH BREAKTHROUGHS

The Mesulam Center continues to make significant research contributions to the Alzheimer's disease and related dementias (ADRD) community.

### Primary Progressive Aphasia

In January, center director Marsel Mesulam, MD, published research on primary progressive aphasia's (PPA) effects on memory in the journal *Neurology*. The primary findings of this study showed that individuals living with the PPA variant, caused by Alzheimer's disease, did not show a significant decline in memory skills over the span of a few years. In comparison, persons with typical types of Alzheimer's disease experienced loss of memory. This study showed that there are different kinds of Alzheimer's disease, one type leading to memory loss and dementia, and the other leading to PPA.

"More research is needed to help us determine what factors allow [people with primary progressive aphasia] to show this resilience of memory skills even in the face of considerable Alzheimer's disease pathology in the brain," Mesulam said.

### SuperAging

Another important research finding related to memory resilience was published this year in the journal *Cerebral Cortex*. The new study, by lead author Tamar Gefen, PhD, shows that cognitive SuperAgers resist the development of fibrous tangles in a brain region related to memory, which are known to be markers of Alzheimer's disease.

These tangles — made from the tau protein — disrupt the cell's transport system, hampering communication within the neuron and preventing nutrients from performing their particular job within the cell. The end result of tangle formation is cell death.

"This finding helps us better identify the factors that may contribute to the preservation of memory in old age," Gefen said. "This research highlights that there are gradients of vulnerability to cell death in the brain."

Read more about the latest research at [brain.northwestern.edu/about/news](http://brain.northwestern.edu/about/news).

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# Recommitting to Diversity and Inclusion

## A NEW TASKFORCE TAKES A TARGETED APPROACH TO COMMUNITY ENGAGEMENT AND RESEARCH RECRUITMENT

**O**n a national level, research studies for Alzheimer's disease and related dementias (ADRD) face a severe lack of racial and ethnic diversity. In June 2020, the Mesulam Center established a taskforce to improve diversity of ADRD research participants. The taskforce is led by Brittanie Muse, MSPH, CCRC, clinical research coordinator, and Darby Morhardt, PhD, LCSW, director of the Outreach, Recruitment and Engagement (ORE) Core.

Through this taskforce and community partnerships, the center continues to work toward equitable research practices and treatment for all diagnosed with dementia and their families. The goal is for our research participants to be reflective of the population of the city of Chicago through community engagement, recruitment, and retention of individuals from underrepresented minoritized communities.

"For the past 25 years, we have always aimed to diversify our cohort of research participants. By creating this taskforce, we are making it an even larger focus at the center," Morhardt said.

Diverse research participants are important in both understanding diseases and developing treatments. Black and Latinx individuals are more likely to develop Alzheimer's disease or dementia, but they are underrepresented in research.



Mesulam Center staff members Sydney Doyle, Abbey Page, and Lisa Rawlani attend the Memory Cafes hosted by South Loop Village.

"In a clinical trial, we try to figure out the course of a disease to develop treatment, or we test a disease treatment for safety and effectiveness," Muse said. "If we don't have a diverse population in clinical trials, the results are going to be skewed. We really have to do our due diligence as scientists to make sure we are including all the populations we are intending to treat."

### Solidifying community partnerships

Since its inception, the taskforce has hosted virtual outreach events with community partners, including South Loop Village, the Francis J. Atlas Senior Center, and the Chicagoland Villages Collaborative. Mesulam Center faculty have presented on brain health basics and SuperAging, outlining things individuals can do to stay cognitively healthy.

These partnerships have been key to the Mesulam Center for decades. For the past 27 years, a partnership with Francis J. Atlas Center has helped to connect and offer educational opportunities for older adults in the South Shore neighborhood of Chicago. The relationship between the two organizations started years ago when the Mesulam Center hosted brain health seminars in conjunction with dance fitness at the Atlas Center. Now, the organizations collaborate to provide sessions on dementia, brain-aging, and healthy memory.

Additionally, a partnership between the Endealeo Institute and the Mesulam Center has been impactful for the older adult community in Washington Heights. During the renovation of the Carter G. Woodson Regional Library, the partnership worked with the library and other stakeholders to develop dementia friendly programs and services.

"One of our goals is to strengthen relationships with our community partners and cultivate new community partnerships," Morhardt said. "In order to strengthen the diversity of research participants, we need to be present and build trust within communities and give back."

### Recruiting a diverse workforce

Additionally, the center was awarded a grant dedicated to improving enrollment of individuals from underrepresented groups for the Alzheimer's Disease Neuroimaging Initiative 3 (ADNI 3) clinical trial. Part of this funding was used to hire another research assistant from a diverse background.

"One of the things that is really important in recruitment of diverse individuals is making sure that you have staff that is reflective of the population you are trying to recruit," Muse said. "It is important for all of our clinical trials and the center at large to make sure we focus on diversity."

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**Learn more about community engagement at [brain.northwestern.edu/community](https://brain.northwestern.edu/community).**

# Mesulam Center Offers Clinical Trials

## ALL STUDIES ARE RECRUITING NEW PARTICIPANTS

**A**t the Mesulam Center, we offer both interventional and observational research studies. Interventional studies offer a new medication or type of therapy, and track the effects over time. Observational studies deepen our understanding of the problem by gathering data for a period of time. Read about our current studies below. All of these studies are actively recruiting new participants.

## Interventional

### Progranulin Gene Mutation Study (INFRONT-3)

This trial is studying an investigational drug for individuals at risk for or diagnosed with frontotemporal dementia (FTD), caused by mutations in the progranulin gene (known as GRN). These mutations reduce progranulin levels in the body and may lead to symptoms of FTD. The purpose of this phase 3 study is to learn whether drug treatment can help sustain levels of progranulin in the brain and delay onset of symptoms or slow disease progression. Participants must have a progranulin gene mutation to be eligible. The study team may be able to provide genetic testing at no cost to potential participants.

### The AHEAD Study (AHEAD 3-45)

This study will test an investigational anti-amyloid drug and its ability to prevent the development of Alzheimer's disease symptoms. Amyloid is a protein fragment that is found in everyone's brains; an increased level of amyloid protein can be related to Alzheimer's disease symptoms such as cognitive impairment. Individuals can be eligible for the study if they are cognitively normal but have intermediate or elevated amyloid. Participants will receive a biweekly or monthly infusion of the drug or a placebo.

In addition to clinical trials, the Mesulam Center is currently enrolling for many other research studies. Our research efforts lead to better understanding of and future treatments for age-related cognitive decline and the diseases that cause it.

## Observational

### Longitudinal Early Onset Alzheimer's Disease Study (LEADS)

This study observes disease progression in people with early-onset Alzheimer's disease (EOAD) from ages 40 to 64. Longitudinal cognitive assessments and biomarker data are collected from both people with EOAD and cognitively healthy participants the same age.

### ALLFTD

This study observes disease progression in individuals with various forms of frontotemporal lobar degeneration (FTLD) causing dementia. Individuals with a strong family history of frontotemporal dementia caused by a known genetic mutation are also eligible to participate.

### Alzheimer's Disease Neuroimaging Initiative 3 (ADNI 3)

This study is working to determine the relationships between clinical, cognitive, imaging, genetic, and biochemical biomarker characteristics of Alzheimer's disease as the pathology evolves from cognitively normal aging to dementia. Current participants are 55 to 90 years old and may be cognitively healthy, have mild cognitive impairment (MCI), or Alzheimer's disease.

### Trial-Ready Cohort for the Prevention of Alzheimer's Dementia (TRC-PAD)

This is an observational study that advances Alzheimer's dementia research by matching cognitively healthy people with clinical trials to prevent the dementia caused by Alzheimer's disease. People who are in the trial-ready cohort are routinely assessed at twice yearly, in-person visits until they are found to be eligible for a clinical trial. Most people enter this study by first participating in a free, online program that tracks cognitive performance on several short tests. Participants must be at least 50 years old and can sign up at [aptwebstudy.org](http://aptwebstudy.org).

**Learn more about our clinical trials at [brain.northwestern.edu/join](http://brain.northwestern.edu/join).**

# Studying Factors that Affect Connectedness in the Buddy Program

**F**or Nila Suresh, participating in the Buddy Program was more than just a yearlong activity she participated in during her first year of medical school. Not only did it give her a new friendship with her buddy, Mike, it also inspired a research study.

Now, as a third-year medical student at Feinberg School of Medicine, Suresh works with Darby Morhardt, PhD, LCSW, and Borna Bonakdarpour, MD, to identify the factors that affect levels of connectedness between the first-year medical students and individuals living with dementia.

The Buddy Program pairs first-year medical students with people living with early-stage dementia for a mutually enriching experience over the course of an academic year. This year, the program had a record number of participants — 21 pairs of medical students and individuals living with dementia. It was a unique year for the Buddy Program because it was hosted entirely virtually due to the pandemic.

As part of Suresh's study, the medical student participants were surveyed on attitudes toward dementia, knowledge, and empathy. They were surveyed again at the end of the year, and a combination of these survey results, the documented number of hours spent together, qualitative data from student journal entries, and post-program focus groups will be used to determine the level of connectedness between each student and their mentor.

Suresh said that many of the individuals living with dementia said in focus groups that the Buddy Program was the only social connection they had during the pandemic. "The program is really enriching and important for all who participate, but especially for those who are living with dementia," she said.

"Being able to have a friendship with someone who is experiencing dementia allows for growth in empathy and personal awareness."

NILA SURESH



Nila and her mentor Mike have stayed connected after the program ended.

The program is also unique because the relationship goes beyond a doctor-patient dynamic. This is intentional; it helps students cultivate real friendships and learn the life experiences of a person living with dementia.

"There is so much you don't learn from textbooks and lectures. Being able to have a friendship with someone who is experiencing dementia allows for growth in empathy and personal awareness," Suresh said.

Morhardt, research professor, and Bonakdarpour, assistant professor of Neurology, were also recognized for their excellence in mentorship during this research study with a teaching pin from the Feinberg School of Medicine's Department of Medical Education.

# Investing in the Buddy Program, Honoring the Miller Family

**W**hen you invest in something, you want to see it grow. You see value in your investment, and you believe the outcome of your investment provides benefit in the future. That's why the Miller Family has supported the Buddy Program at the Mesulam Center for Cognitive Neurology and Alzheimer's Disease.

The Buddy Program, which began in 1997, pairs first-year medical students with individuals living with early-stage dementia over the course of an academic year. Glen and Wendy Miller, and their daughter Lauren, through the Glen and Wendy Miller Family Foundation, began supporting the Buddy Program in 2008. This year, it will be named after the family as the Glen and Wendy Miller Family Buddy Program.

The Miller family knows the effects of dementia well. They took care of Wendy's mother, Marcy Raftenberg, after she was diagnosed with Alzheimer's disease dementia. They served as caregivers for 17 years, and after she passed away, they wanted to improve the quality of life for individuals like Marcy.

The family met Darby Morhardt, PhD, LCSW, and were inspired by the innovative Buddy Program.

"The concept of exposing new, young doctors to Alzheimer's patients has long-range benefit for the doctors, the patients, and the patients' families."

GLEN MILLER

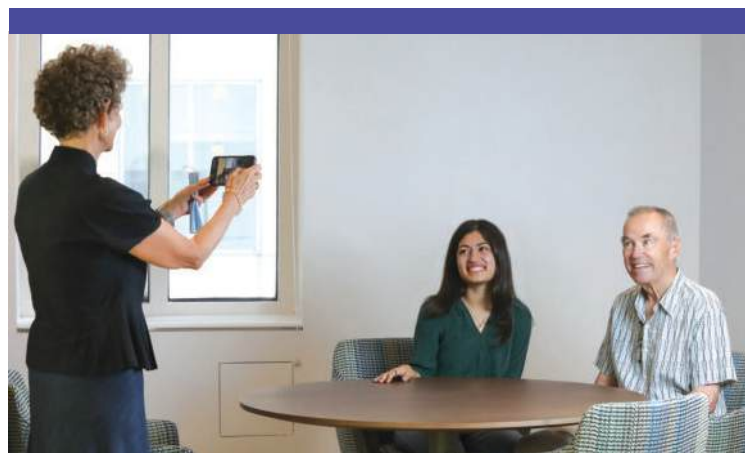
The Buddy Program was developed on the premise that, despite a dementia diagnosis, people can still maintain a meaningful quality of life. Additionally, educating future physicians about dementia and building empathy for patients outside of the clinical setting is critical.

"The concept of exposing new, young doctors to Alzheimer's patients has long-range benefit for the doctors, the patients, and the patients' families," Glen Miller said. "With the increasing numbers of individuals aging and living longer, we know that Alzheimer's will increasingly affect our world."

The idea for the program came from the experience of a retired Northwestern physician who was diagnosed with Alzheimer's disease. After the diagnosis, he was disappointed that he could no longer share his experience and knowledge in a meaningful way. Although he ultimately stopped working as a result of his cognitive decline, he was still able to impart valuable medical information and mentor an interested medical student.

The program offers an opportunity for both the person with dementia and their family to share their experiences with the illness, while giving medical students the opportunity to get to know someone with dementia in the early stages, as a person and a friend.

"It's inspiring the way the students become like family with their mentors, and the caregivers benefit greatly as well," Lauren said. "We are proud to be associated with the program."



Second-year medical student Sareen Ali and her Buddy Program mentor Jim were able to meet in person in August 2021.

## SUPPORT THE MESULAM CENTER

Generous individuals are catalysts in supporting innovative medical research. If you are interested in making a gift to support the work of the Mesulam Center, contact Jordan Sund at [jordan.sund@northwestern.edu](mailto:jordan.sund@northwestern.edu) or (312) 503-2706, or make a gift online at [brain.northwestern.edu/give](https://brain.northwestern.edu/give).

# Remembering Those We Have Lost

In 2021, we lost many members of our research participant community. As of September, we have lost 24 research participants, all of whom have donated their brains.

May we always remember their selfless contributions to cognitive aging research and their vibrant spirits.

- |                              |                        |
|------------------------------|------------------------|
| <b>Elizabeth Lautner</b>     | <b>Ruth Kahl</b>       |
| <b>Joel Raphaelson</b>       | <b>Mary Baker</b>      |
| <b>Leatrice Evelyn Smith</b> | <b>Charles Smith</b>   |
| <b>Cornelius Kruchten</b>    | <b>Joanne Scharnak</b> |
| <b>Patti Lovaas</b>          | <b>Debra Belcher</b>   |
| <b>Jerry Brandenburg</b>     | <b>Prabhjot Singh</b>  |
| <b>Glorye Wool</b>           | <b>Penny Parsons</b>   |
| <b>Martin McGrath</b>        | <b>Alfred Johnson</b>  |
| <b>Leona Green</b>           | <b>Steven Rice</b>     |
| <b>David Eisen</b>           | <b>Wendy Taylor</b>    |
| <b>Anne Schank</b>           | <b>Anita Smith</b>     |
| <b>Virginia Harnett</b>      | <b>Gustave Aberle</b>  |

## Mesulam Center Editorial Committee

Mesulam Center News is published annually for research participants and friends of the Mesulam Center for Cognitive Neurology and Alzheimer's Disease.

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## PUBLICATIONS AND AWARDS

### AUGUST 2020 - AUGUST 2021

Mesulam Center investigators received major grants that advance the field of Alzheimer's disease and related dementias. Additionally, the P30 from the National Institute on Aging was renewed this year for another five years.

### 37 PUBLICATIONS

#### NEW GRANTS:

**Margaret Flanagan, MD: Alzheimer's Drug Discovery Foundation** Retinal Changes in Alzheimer's Disease (AD) Correlated with Cerebral Amyloid Staging, A Promising Early Biomarker in AD

**Margaret Flanagan, MD: National Institute on Aging** Investigating the Role of Neuroinflammation in Limbic-predominant Age Related TDP43 Encephalopathy

**Margaret Flanagan, MD, co-principal investigator: National Institute on Aging** Exploring the Origins of Myelin Abnormalities in Normal Aging and in Vascular Dementia

**Ian Grant, MD: ALECTOR** Prot#AL001-3: A Phase 3, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to Evaluate the Efficacy and Safety of AL001 in Individuals at Risk for or With Frontotemporal Dementia Due to Heterozygous Mutations in the Progranulin Gene

**Emily Rogalski, PhD: National Institute on Aging** Alzheimer's Disease Neuroimaging Initiative (ADNI3) [Diversity Taskforce Project]

**Emily Rogalski, PhD: National Institute on Aging** Study to Uncover Pathways to Exceptional Cognitive Resilience in Aging

**Darby Morhardt, PhD, LCSW: Glen and Wendy Miller Family Foundation** The Glen and Wendy Miller Family Buddy Program, The Glen and Wendy Miller Social Work Fellowship in Neurocognitive Disorders

**P30 Grant Renewed** See story on page 9.

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