

# CNADC NEWS

*Produced by the Cognitive Neurology and Alzheimer's Disease Center*

## **A New Home for the CNADC of Tomorrow: The Mesulam Center for Cognitive Neurology and Alzheimer's Disease**

In 2015, Northwestern University Feinberg School of Medicine launched an initiative to raise \$10 million to solidify the future of its Cognitive Neurology and Alzheimer's Disease Center (CNADC). The funds would provide critical additional space for the center in a setting that would integrate clinical and basic science research. Additionally, the campaign aimed to establish a professorial

chair and robust endowment for both research and education that would aid in recruiting both young faculty and established leaders in neurodegenerative medicine and cognitive neuroscience. The plan also sought to name the center after M.-Marsel Mesulam, MD, the Ruth Dunbar Davee Professor of Neuroscience—a fitting tribute to a renowned leader in Alzheimer's disease research. The medical school recently

"Multidisciplinary integration is essential for addressing Alzheimer's disease, primary progressive aphasia, and related disorders," says Mesulam, also the center's director. "The new space will allow our basic science laboratories to be located next to laboratories for imaging and cognitive testing. Faculty from different disciplines will work collaboratively, learn from each other, and train the next generation of clinicians

and investigators. The custom-built space will enable a much-needed expansion of the research enterprise and accelerate the pace of discovery. The goal is to make our patients and their families the beneficiaries of all advances."

The new headquarters will be twice the size of the center's current space, allowing current programs to grow while

"Faculty from different disciplines will work collaboratively, learn from each other, and train the next generation of clinicians and investigators."

— M.-Marsel Mesulam

announced that the campaign has reached its target and the Mesulam Center for Cognitive Neurology and Alzheimer's Disease will move into its new quarters by November 2018.

novel ones are initiated through strategic recruitments. Features will include a beautiful reception area; a state-of-the-art conference space with teleconferencing capability; an imaging suite for advanced computerized analyses;



*The Mesulam Center for Cognitive Neurology and Alzheimer's Disease will be located in the Tarry Research and Education Building.*

## COGNITIVE NEUROLOGY AND ALZHEIMER'S DISEASE CENTER

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*The advisory board was founded by the late Jerome Rosenstone, who served as chair from 1998 to 2008.*

The CNADC is one of 31 Alzheimer's Disease Centers funded by the National Institute on Aging, National Institutes of Health.

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Dear friends and colleagues,

There is excitement in the air! By this time next year, the CNADC will be moving into its new home on Tarry 8. The move comes at a time when critical space shortages make it increasingly difficult to let successful programs grow and to initiate new ones. This is why Feinberg dean Eric Neilson and his administration launched a major campaign to fund construction of a new space for the CNADC.

I am delighted to announce that the initial target of \$10 million has been reached. The new space, which will double our existing square footage, is currently being designed and will be available for occupancy by November 2018. The medical school has also given me the incredible honor of naming the center after me. I must confess that when this possibility was first suggested, I did not take it all that seriously. The prospect was too distant, and the honor too great, to contemplate. Words fail to convey the sense of both humility and pride I feel at the outcome.

I am grateful for the generosity of so many friends of the CNADC, and the time will soon come to formally recognize and thank those who have enabled this remarkable turn of events. I do want to single out the extraordinary role of Ken and Ruth Davee in our history. In 1994 a major gift from the Davees led to the establishment of the center. Through the years, the Ruth Dunbar Davee (formerly the Ruth Evelyn Dunbar) chair has allowed me to serve as the center's director. Seed grants for new initiatives, personally approved by Ruth, led to the development of research programs on primary progressive aphasia and SuperAging—two programs that have since attracted National Institutes of Health funding and international recognition. More recently, the Davee Foundation has made extraordinary contributions that have helped enable our move to Tarry 8, as well as the endowment of a new professorial chair at the CNADC and the naming of the center. On behalf of the entire CNADC, I want to express my gratitude to the board of the Davee Foundation and to the visionary commitment of its executive administrator, Craig Grannon.

Yet there is more to do. The new space provides opportunities to recruit young investigators as well as established leaders, both of whom will bring new ideas and initiate research programs. There will be philanthropic opportunities to support these developments by endowing fellowships, lectureships, and professorships at the CNADC. Another goal is to expand our Neurobehavior Clinic—currently located at the Arkes Pavilion—where new discoveries are translated into innovative patient care modalities. It serves as a crucial interface between our clinical and research activities, and as our research grows, so will our clinical enterprise.

Please watch for more news on our new space and additional CNADC developments in the next issue of our newsletter. Until then, I wish you and your families happy and healthy holidays.

A handwritten signature in black ink that reads 'M.-Marsel Mesulam MD'.

M.-Marsel Mesulam, MD

CNADC director and Ruth Dunbar Davee Professor of Neuroscience

# Alzheimer Day 2017

In May, the CNADC hosted the 23rd annual Alzheimer Day, highlighting Northwestern research in Alzheimer’s disease and related disorders. More than 400 community members, medical professionals, scientists, researchers, and CNADC friends and families attended the event, which was supported by CNADC staff.

John C. Morris, MD, the Friedman Distinguished Professor of Neurology and director of the Charles F. and Joanne Knight Alzheimer Disease Research Center at Washington University School of Medicine in St. Louis presented the Mendelson Lecture, “The Biomarker Revolution in Alzheimer’s Disease.”

Northwestern clinicians and scientists presented 49 posters during the event, with the 2017 Marie and Carl Duncan Prize in Memory Research going to Borna Bonakdarpour, MD, for his “Altered Language Network Connectivity in Primary Progressive Aphasia.”

The CNADC’s Darby Morhardt, PhD, LCSW, moderated the afternoon session on “Living with Dementia: Fostering Connection, Creativity, and Contribution.” The session honored the Glen and Wendy Miller Alzheimer’s Family Support Program and celebrated the 20th anniversary of the Buddy Program, a unique opportunity for first-year medical students to build friendships—outside a clinical setting—with people who have Alzheimer’s disease or related disorders (see article on page 4). Wendy Miller spoke on behalf of the Miller family about their support for the Buddy Program and other CNADC life enrichment programs.

Morhardt was joined by current and former Buddy Program participants, including mentors Katrina Moncrief and Irene Dove and buddies Jakita Baldwin, Warren McGee, and Annika Nilsen. A panel discussion about the CNADC Quality of Life enrichment programs followed, with doctors Bonakdarpour, Christine M. Dunford, and Natasha Ritsma; social worker Lauren Dowden; and Jennie and Bill Finik, who offered insight into their experience living with an Alzheimer’s diagnosis.



Top (left to right): Robert Mendelson, John C. Morris, Linda Mendelson, David Mendelson  
 Middle (left to right): Jakita Baldwin, Annika Nilsen, Katrina Moncrief, Warren McGee, Irene Dove  
 Above left (left to right): Borna Bonakdarpour and John Disterhoft  
 Above right: M.-Marsel Mesulam  
 Far left: Jennie and Bill Finik  
 Left: Wendy Miller

## A New Home for the CNADC of Tomorrow

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an electrically and acoustically shielded space for electrophysiological recordings; video-linked testing rooms; and an enlarged basic research laboratory. The lab will integrate the brain bank of the CNADC with the cognitive morphometry laboratory and its microscopy suite. Each feature was chosen to address the pressing needs of the most successful CNADC programs and their likely future trajectories.

CNADC faculty members have begun to work with architectural firm Harley Ellis Devereaux on the design of the new center, which will be located on the eighth floor of the Tarry Research and Education Building. Tarry, with 16 floors dedicated to education and research, was built in 1990 through a leadership gift from George W. and Edwina S. Tarry, major benefactors of the medical school and Northwestern's School of Education and Social Policy.

The CNADC has occupied its current location since the center's founding more than 20 years ago. During that time, staff and funding have more than quintupled, and many fledgling initiatives have expanded to become independent research programs. The new location will accommodate such development, maximize synergies among individual programs, and pave the way for new directions in promising areas.

## Buddy Program Marks 20th Year

Twenty years ago, the Buddy Program was developed as an experiential learning and mentorship program for first-year medical students and people diagnosed with dementia. The concept originated when a physician, after being diagnosed with Alzheimer's dementia, was faced with losing his life's work. Although he could no longer practice medicine, he was still able to impart valuable knowledge by mentoring a medical student. The student, in turn, could benefit from the physician's experience and perspective as well as develop a better understanding of the effects of cognitive decline. Rather than engaging in a hierarchical clinical relationship, the student and patient were "buddies" sharing experiences.



The program—rooted in the belief that people with dementia have the capacity to make meaningful contributions to society—is based on relationships, conversation, dialogue, and reciprocity, empowering people with dementia in a world where they are often marginalized.

Buddies plan a year of regular meetings around mutually enjoyable activities, such as visiting museums, attending concerts, sharing meals, or simply going for walks. Participants attend a preprogram Match Day, where they meet informally to share information about themselves.

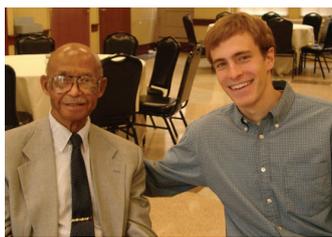
Over the past 20 years, 220 buddy pairs have been matched. Students' activity journals and evaluations of their knowledge and attitudes toward people with dementia demonstrate an evolution of awareness and deepened understanding. In turn, people with dementia enjoy the opportunity to influence future physicians' knowledge and approach to those with their disease. Families appreciate the chance for their loved ones to participate in meaningful activities that focus on remaining strengths.

Generously supported by the Glen and Wendy Miller Family Foundation and by a Northwestern Alzheimer's Disease Core Center grant from the National Institute on Aging, the program has been emulated at 12 universities nationally and internationally, with several programs in development.

*The Buddy Program: A Manual for Developing an Experiential Learning and Mentorship Program for Persons with Dementia* is available by contacting Darby Morhardt, PhD, LCSW, at [d-morhardt@northwestern.edu](mailto:d-morhardt@northwestern.edu) or 312-908-9432.



*“My mentor and her husband have taught me so much about family and caregiving—and especially about how grief and gratitude can be intertwined. Spending time with them has undoubtedly shaped my trajectory as a physician. Because of this experience, I feel certain that empathizing with and understanding how to best help caregivers and families is instrumental to providing care to patients with Alzheimer’s or other dementias. I feel much better equipped to do that now, and I feel that my potential to be a good physician to patients with dementia and their families is so much greater.”*



*“Not only do I think my time with my mentor in the Buddy Program will augment my compassion and understanding as a physician, I also think it will enhance the lens through which I interact with all my friends, family, and community members. Whether or not I choose to pursue a career in neurology, my time with my mentor will greatly impact the importance I will place on each unique patient narrative.”*

### Buddy Program Goals

- Educate medical students about Alzheimer’s and related conditions by increasing their knowledge of dementia; heightening their awareness of the skills and strengths that remain in people with cognitive impairment, especially in earlier stages of illness when they appear normal but may have significant cognitive limitations; providing opportunities to see firsthand how people with early-stage disease respond to their own changing abilities; and familiarizing students with daily care issues of people with dementia and their families—and with the most effective ways of communicating with them.
- Introduce students to research and practice opportunities in fields related to aging and memory impairments.
- Provide people with dementia an opportunity to serve as mentors to future doctors.
- Provide people with dementia an opportunity for life enrichment.



*“While I have always been interested in neuroscience and Alzheimer’s disease, the Buddy Program empowered me to continue pursuing my interest in neurology. Knowing that there is still a huge need for better treatments for Alzheimer’s disease will encourage my research interests. By actually seeing the impact of the disease on a patient and his family, I have a better sense of the urgency to find better treatments and to further the field of neuroscience.”*

## Specialized Online Therapy Helps People with Dementia Recall Lost Words

A novel web-based speech therapy program at the CNADC has allowed people with dementia-related language problems to significantly improve their ability to recall words they had “lost.” A new Northwestern Medicine study showed that one woman could once again identify the tulips and daffodils in her garden, and one man’s ability to order his favorite meal from the drive-through was restored.

People with Alzheimer’s dementia or primary progressive aphasia often have language problems, struggling to retrieve the name of a grandchild or find the words to order dinner in a restaurant. But their language impairment often goes untreated because most speech-language pathologists are trained to help children or people who lost speech after a stroke—not those with dementia.

Northwestern scientists are closing that gap by developing Communication Bridge, a program in which specially trained speech-language pathologists offer personalized therapy over the internet to people with dementia-related language impairment. A new pilot study has shown that participants made significant improvement in recalling words after two months of therapy and maintained that progress after six months.

“These improvements are especially exciting because we would expect declines, but these people are holding onto these gains,” says lead study author Emily Rogalski, associate professor at the CNADC. Early results of the program were published in *Alzheimer’s and Dementia: Translational Research and Clinical Interventions*.

“There’s a misconception that speech-language pathologists can’t help people with dementia, but in fact, they have



many tools that can be helpful,” Rogalski says. “This is not a cure, but we may be able to delay some of the progression and maximize people’s remaining abilities.”

The program starts by determining a person’s challenges and strengths, followed by eight therapy sessions with a specialized speech pathologist via video chat. Videos reinforce the sessions, and home assignments like virtual flashcards help support language memory.

“It doesn’t matter where the person lives—you can get the same quality of care anywhere in the world via the internet,” Rogalski says. Feedback from participants, caregivers, and therapists was overwhelmingly positive, the authors report.

“A lot of people said they went from feeling like they had no control over their disease to feeling like they were really fighting back and empowered,” says speech-language pathologist Becky Khayum, a study consultant. “They felt like they could more fully participate in life in spite of their disease.”

The program also helped participants read novels again, a pleasure some had lost to their disease, by simultaneously reading it and listening to an audiobook.

Communication Bridge grew out of conversations with people with dementia and their families, who traveled from around the country to the CNADC for evaluation and treatment. When they returned home, they were frustrated that they didn’t have access to a specialized speech-language therapist.

The study, supported by the Alzheimer’s Association, the Association for Frontotemporal Degeneration, Run4Papa, and the National Institutes of Health, is still enrolling participants. For more information, visit [www.brain.northwestern.edu/research/studies](http://www.brain.northwestern.edu/research/studies). —Marla Paul

### Connect with the CNADC!

Follow the CNADC on social media to see the latest news, research updates, and upcoming events.



[www.facebook.com/cnadc](http://www.facebook.com/cnadc)



[www.twitter.com/cnadc](http://www.twitter.com/cnadc)

## Memory Loss Not Enough to Diagnose Alzheimer's

Relying on the clinical symptoms of memory loss to diagnose Alzheimer's disease may cause physicians to miss other forms of dementia caused by Alzheimer's that don't initially affect memory, according to a new Northwestern Medicine study.

"These individuals are often overlooked in clinical trial designs and are missing out on opportunities to participate in clinical trials to treat Alzheimer's," says lead study author Emily Rogalski, associate professor at the CNADC.

Alzheimer's can cause language problems; disrupt behavior, personality, and judgment; and even affect perception of objects in space. If it affects personality, the disease may cause lack of inhibition. "Someone who was very shy may go up to a grocery store clerk, who is a stranger, and try to give her a hug or kiss," Rogalski says.

This all depends on what part of the brain is attacked early in the disease. In the study, the authors identify the clinical features of people with primary progressive aphasia (PPA), a rare dementia that causes progressive decline in language abilities. Early in PPA, memory and other thinking abilities are relatively intact. The study demonstrates that a patient's clinical symptoms aren't sufficient to determine whether someone has PPA due to Alzheimer's or another type of neurodegenerative disease.

A definitive diagnosis of the specific disease causing dementia can only be made with an autopsy. However, emerging evidence suggests that an amyloid PET scan—an imaging test that tracks the presence of an abnormal protein whose accumulation in the brain is a hallmark of Alzheimer's—may be used during life to identify the neuropathological cause and determine the likelihood of Alzheimer's disease pathology.

Northwestern scientists looked at people in mild stages of language loss caused by Alzheimer's disease and described their brain atrophy based on MRI scans and their results on cognitive tests.

"We wanted to describe these individuals to raise awareness about the early clinical and brain features of PPA to develop metrics that would advocate for their inclusion in

### Dementia Friendly Illinois

The CNADC is excited to be involved in a new Dementia Friendly America initiative.



This national program, in partnership with the National Association of Area Agencies on Aging and LeadingAge, supports the development of dementia-friendly communities across the US by increasing community and system capacity to enhance quality of life for people with dementia and their care partners.

Spearheaded by the Illinois Cognitive Resources Network (ICRN)—a collaboration of Alzheimer's assistance centers, advocacy organizations, and public-health and aging-and-disability networks—a statewide workshop was held in March to explore how to build a Dementia Friendly Illinois.

Over 80 participants discussed the experiences of people and families dealing with dementia and what is needed to provide better support in the state. They also joined in regionally focused discussions on how to engage local communities to best support people with dementia, leaving the workshop energized and motivated to transform their communities. The ICRN will provide ongoing resources and technical support to the initiative, as well as maintain a list of dementia-friendly communities in the state.

clinical trials targeting Alzheimer's disease," Rogalski says. "These individuals are often excluded because they don't have memory deficits, but they share the same disease that's causing their symptoms."

The study was published online in the journal *Neurology* in August. CNADC director M.-Marsel Mesulam is senior author of the paper. —Marla Paul

## Mild Cognitive Impairment: A Diagnostic Milestone Offering the Opportunity to Reduce the Risk of Dementia

Some people over age 65 experience what is referred to as age-related cognitive decline, or “normal” aging, which may be frustrating but not limiting. Others, however, will experience more severe decline leading to a state of dementia—a level of decline severe enough to initially interfere with routine daily activities and later even with simple functions. The most common cause of dementia in those over 65 is Alzheimer’s disease.

Dementia doesn’t happen overnight; rather, there is a very slow decline from normal aging to a stage called mild cognitive impairment (MCI), a term originally coined in 1997 by Ron Petersen of the Mayo Clinic. MCI provides a window of opportunity to intervene before more damage occurs in the brain to cause dementia.

MCI is diagnosed when a person experiences a decline on neuropsychological tests of memory or other cognitive functions (language, executive functions, visuospatial skills) but shows no evidence of reduced ability to perform activities of daily living (ADLs). Reports on ADLs are typically obtained from someone who knows the person well enough to notice even subtle changes in behavior on a daily basis.

When MCI is characterized by a primary memory impairment, it is known as amnesic MCI, or aMCI. People with aMCI may forget conversations and recent events within a short amount of time, or may begin to misplace important belongings or repeat themselves. On objective neuropsychological evaluation, they may forget a list of 10 words they learned 15 minutes prior but may perform normally for their age on tests of attention, language, or reasoning.

### Why is it important to study MCI?

People diagnosed with MCI are at an increased risk of developing dementia due to Alzheimer’s disease or other neurodegenerative brain diseases. Thus, clinicians recommend they be evaluated regularly to determine whether cognitive symptoms are improving, staying the same, or worsening over the course of a year. A major research goal is to improve

diagnosis and to design interventions and therapies that prevent further cognitive decline and dementia in MCI.

The brains of people with MCI already exhibit the molecular changes evident in those with Alzheimer’s dementia. Studying MCI provides an opportunity to investigate very early stages of dementing illnesses, allowing the possibility for early intervention.

Research is attempting to identify the presence of Alzheimer’s disease ever earlier, even when no overt symptoms of cognitive failure are present. Currently, biomarkers associated with the molecular pathology of Alzheimer’s are detectable in special PET scans of the brain or in cerebrospinal fluid. People without cognitive symptoms but with elevated biomarkers may be at greater risk for progressing to dementia than those without elevated biomarkers. “Subjective cognitive complaints”—experiencing cognitive decline without objective evidence, especially in people with elevated biomarkers—are now associated with very early brain changes that could increase the risk of dementia.

### MCI studies at Northwestern

The CNADC supports MCI studies in several ways:

1. *A registry of people clinically diagnosed with MCI.*  
Participants are followed annually and notified of their clinical status. Demographic information, health history, and neurological and neuropsychological tests are collected and completed annually, and data are maintained locally as well as submitted to a national database containing data from all Alzheimer’s centers funded by the National Institute on Aging. Data are shared with researchers, and participants are periodically invited to participate in other studies to improve diagnosis or to treat MCI.
2. *A study conducted by Amani Fawzi, MD, of Northwestern’s Department of Ophthalmology, on the use of noninvasive eye examinations to diagnose early Alzheimer’s disease.*  
It is unclear whether some neurodegenerative changes due to Alzheimer’s can be detected in the retina. The

study involves an eye examination with a special noninvasive instrument that allows visualization of retina cells.

3. *A study on the impact of treatments during sleep to improve memory.* Roneil Malkani, MD, Phyllis Zee, MD, and Ken Paller, PhD, with neuroscience graduate student Nelly Papalambros, completed a study showing that healthy older adults who were exposed to soft sounds during sleep had enhanced slow-wave activity and performed better on a memory test the next day. A decrease in slow-wave activity—a measure of deep sleep—is related to the presence of memory problems in older adults. A new study is in progress to determine whether the technique can also enhance memory in people with MCI.
4. *A study conducted by Joel Voss, PhD, on transcranial magnetic stimulation to improve memory function in MCI and determine whether associated memory loss can be reversed.* TMS is applied to the skull, transmitting a temporary effect to underlying tissue to connect different regions in the brain. Connections among different regions are important for normal brain functions, including memory.

To learn more about these studies, visit [www.brain.northwestern.edu](http://www.brain.northwestern.edu) or call 312-926-1851.

## REACH to Faith 2.0 Receives Funding from Northwestern University Alliance for Research in Chicagoland Communities

REACH to Faith 2.0 seeks to build the capacity of the REACH (Research and Education for African American Caregiver Health) to Faith program, a community engagement partnership between Northwestern and the Endeleo Institute, the nonprofit arm of Trinity United Church of Christ on Chicago's Far South Side, with seed funding from Northwestern's Alliance for Research in Chicagoland Communities at the Center for Community Health.



African Americans represent 39 percent of the local population age 65 and older; however, they're two to three times more likely to be diagnosed with dementia than white populations. In spite of these statistics, African Americans receive less dementia care and education.

During the past year, the Endeleo Institute spearheaded a community-led, \$10 million restoration of the Carter G. Woodson Regional Library, which is nearing completion. The REACH 2.0 project brings together city agencies, area research and academic institutions, and community members to transform the Woodson Library into the city's first dementia-friendly library. (See the sidebar on page 7 for more information on the Dementia Friendly America initiative).

The project aims to increase awareness and understanding of health research about dementia; identify informative and culturally appropriate health research findings for community members living with dementia and their caregivers; enhance the accessibility and usability of the evidence for a faith-based audience; collate data about community priorities for those living with dementia; and use findings to implement a dementia-friendly library pilot.

A library health advisory board of academic and community stakeholders will guide faith-based community members to disseminate and implement culturally appropriate, dementia-friendly resources and program interventions for people with dementia and their families in the African American community.

For more information, contact Melvin Thompson, MBA, at [mrthompson@endeleoinstitute.org](mailto:mrthompson@endeleoinstitute.org) or Darby Morhardt, PhD, LCSW, at [d-morhardt@northwestern.edu](mailto:d-morhardt@northwestern.edu).

## STUDIES

### Tele-Savvy Study Enrolling Dementia Family Caregivers

The CNADC is recruiting participants for a Tele-Savvy study that will test the efficacy of an online educational program for family caregivers of people with Alzheimer's disease and other dementias. Tele-Savvy is adapted from the in-person Savvy Caregiver program, which trains people providing care for those living with Alzheimer's.

The logo for Tele-Savvy, featuring the text "Tele-Savvy" in a dark blue font with a small green leaf icon above the "v" in "Savvy".

The CNADC is one of the lead centers recruiting more than 270 caregivers, with a goal of giving them additional skills to help decrease depression, stress, and caregiver burden while maintaining optimal function and quality of life for their family members with dementia. Savvy Caregiver has demonstrated its effectiveness in decreasing caregivers' stress and burden and improving their sense of caregiving mastery. A pilot Tele-Savvy program has shown similar positive results.

Participants will engage in professionally led small-group, 1.5-hour videoconferences held over 7 consecutive weeks. Participants watch video lessons meant to inform and improve caregiving; daily videos are 10 to 25 minutes long and can be viewed whenever and as often as participants wish.

Some participants will begin immediately; others will take part six months after enrolling. Among those asked to wait, some will join a Healthy Living program and some will continue with their normal caregiving routine. Healthy Living involves seven weekly group videoconferences along with daily video lessons to be viewed at participants' leisure. Assignments will be random.

All participants will be asked to complete five study interviews over the course of a year, and some will be asked to participate in an additional in-depth interview about their experience. Caregivers will be offered a \$25 gift card for each interview in which they participate.

Interested caregivers can contact **Joshua Kaplan-Lyman, LCSW**, at 312-503-5209 or [JKL@northwestern.edu](mailto:JKL@northwestern.edu).

### Memory Improvement through Nicotine Dosing Study

While we're all forgetful from time to time, as we age we expect to retain our ability to think and remember. Mild cognitive impairment (MCI) is diagnosed when memory problems become



more apparent than would be expected in normal aging. Symptoms include memory loss, attention problems, and mild difficulties learning and retaining new information.

The nicotine patch, a typical smoking cessation tool, has been demonstrated to improve memory in older adults with MCI. Ian Grant, MD, and his team at the CNADC are collaborating with Vanderbilt University and the University of Southern California's Alzheimer's Therapeutic Research Institute to conduct a new treatment study funded by the National Institute on Aging.

The study will investigate whether daily transdermal nicotine is able to produce significant cognitive, clinical, and functional improvement in participants with MCI. Nicotinic receptors in the brain have long been known to play a critical role in memory function, with nicotine improving attention, learning, and memory function.

The two-year study will enroll 300 participants, who will receive either transdermal nicotine, beginning at 7 and increasing to 21 milligrams per day, or a placebo skin patch. Participants are equally likely to receive the nicotine patch or the placebo.

Healthy, nonsmoking adults ages 55 and older, who either notice changes in their memory or whose family members notice memory changes, may be eligible. Participants will have extensive memory and cognitive testing as part of the screening process. Some participants may also be asked to participate in other optional substudy procedures.

Participants are required to have a study partner, such as a family member, close friend, or caregiver, who will accompany them to each appointment. Participants must know their study partners well and spend a minimum of 10 hours a week with them.

For more information or to participate, contact **Jordan Robson** at 312-503-5212 or [jordan.robson@northwestern.edu](mailto:jordan.robson@northwestern.edu).

### **Why nicotine?**

Neurotransmitters are chemicals in the brain, released between neurons, that act as messengers of information throughout the brain. From previous research, we know that nicotine stimulates a receptor site for the neurotransmitter acetylcholine, which is important for thinking and memory. Nicotine has produced only small benefits in people with Alzheimer's disease, which may be because those with the disease have lost too many of these receptors, making nicotine less effective.

In MCI, however, people still have many of these receptors, which makes nicotine more effective for memory improvement. In an earlier study at Vanderbilt University, 74 adults with MCI were prescribed nicotine or placebo patches for six months. Those using the nicotine patch saw improvement in attention and memory, and there were no serious side effects or signs of nicotine withdrawal; these results are encouraging and justify this larger study.

## **Research in Frontotemporal Dementia**

The Advancing Research and Treatment for Frontotemporal Lobar Degeneration (ARTFL) project is a nationwide effort to conduct clinical research on patients with frontotemporal lobar degeneration (FTLD) syndromes. The CNADC is one of 14 sites throughout the US and Canada enrolling participants for on-site evaluations. The goal is to support the development of therapies and diagnostic tools to combat dementia associated with FTLD.



### **Why is it important?**

FTLD syndromes are rare neurodegenerative diseases that gradually affect the ability to behave appropriately, empathize with others, learn, reason, exhibit good judgment, communicate, and carry out daily activities. There are four clinical dementia syndromes associated with FTLD: behavioral variant frontotemporal dementia, primary progressive aphasia, corticobasal degeneration, and progressive supranuclear palsy. Some people with amyotrophic lateral sclerosis also have dementia associated with FTLD. The onset of these diseases tends to occur before age 65, and while there is currently no treatment or cure, some medications and lifestyle changes can help relieve symptoms. ARTFL aims to establish a registry of people who will be ready to enter a clinical trial once an appropriate treatment is identified.

### **What is involved?**

Study visits will include cognitive testing, neurologic research exams, collecting medical and family history, and giving a blood sample. Examinations will not yield information that is clinically useful to individual participants but rather will provide information to improve care and treatment. Healthy close relatives of people with genetic causes or a strong family history of FTLD may also be enrolled. The information will also be used to discover new biomarkers for disease, to standardize diagnostic criteria, and to identify a large group of potential participants for clinical trials of new therapies.

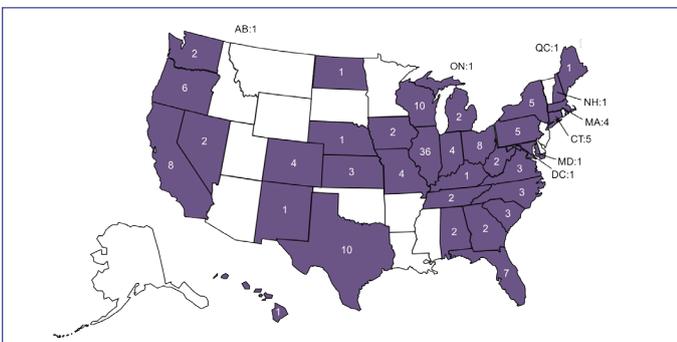
ARTFL is funded by the National Institutes of Health and the National Institute of Neurological Disorders and Stroke. For more information or to get involved, visit [www.brain.northwestern.edu/research/studies/ARTFL](http://www.brain.northwestern.edu/research/studies/ARTFL) or [www.rarediseasesnetwork.org/cms/artfl/about-us](http://www.rarediseasesnetwork.org/cms/artfl/about-us).

## NIH Funding for Three PPA Studies

The CNADC is a national referral center for primary progressive aphasia, a dementia syndrome in which people experience a progressive loss of language abilities. The PPA Research Program at the CNADC currently serves people diagnosed with PPA and their families from across the US and Canada. Three of the program's major projects were recently awarded five-year grants by the National Institutes of Health. Each project has set new goals for the next five years.

The Language in Primary Progressive Aphasia project, led by CNADC director M.-Marsel Mesulam, is beginning its 11th year of funding from the National Institute on Deafness and Other Communication Disorders. In its next phase, the project will use innovative technology such as eye tracking to provide a window into how people process words and pictures and will examine the relationship between clinical and neuroanatomical features of those with PPA.

The Determinants of Neurodegenerative Decline in Primary Progressive Aphasia project, led by Emily Rogalski, is entering its sixth year of consecutive funding from the National Institute on Aging. For the next five years, the project will quantitatively characterize over time the clinical, cognitive, functional, neuroanatomical, and molecular features of people with PPA. It will use tau PET imaging, a relatively new in vivo biomarker, which measures molecular abnormalities in the brain during life.



The PPA Research Program serves people from more than 30 states and provinces.



Researchers in the Northwestern PPA Research Program gathered in May to share their progress over the past 10 years.

State-of-the-art magnetic resonance imaging is planned for both projects, which will allow for submillimeter detection of structural brain changes. Collectively these studies are expected to sharpen understanding of the symptoms of PPA, improve the precision with which we can trace and predict the tempo of disease progression over time, and clarify the diagnostic features of PPA caused by Alzheimer's versus frontotemporal degeneration—and ultimately inform treatment development, clinical trial design, and medication management.

The projects have allowed for new training opportunities for scientists, including postdoctoral fellows JungMoon Hyun and Matthew Nelson, who joined the team last spring and will help fulfill the projects' goals.

A third project, Communication Bridge, received funding to test the usefulness of a web-based intervention for people with PPA (see page 6).

The PPA Research Program is dedicated to developing new educational materials for people with a PPA diagnosis and their families, improving clinical and community recognition of the syndrome, and improving access to relevant clinical trials. More than 160 participants diagnosed with PPA have been enrolled in what is one of the largest PPA studies to date, whose research has generated more than 75 scientific journal articles over the past 10 years.

Once a participant is enrolled, the PPA research program provides compensation for the participant and one companion. Those interested in participating may contact Benjamin Rader at 312-908-9681 or [benjamin.rader@northwestern.edu](mailto:benjamin.rader@northwestern.edu).

## Alzheimer's Disease Neuroimaging Initiative

The Alzheimer's Disease Neuroimaging Initiative (ADNI) is a landmark research study funded by the National Institutes of Health. Begun in 2004, the observational and longitudinal study follows people over time and measures biomarkers (substances that can indicate normal or disease processes in the body) in both blood and cerebrospinal fluid, using MRI and positron emission tomography (PET) imaging to determine and evaluate predictors of cognitive decline.

PET scanning can produce pictures of different body processes. State-of-the-art brain imaging techniques are used in ADNI to monitor brain levels of tau and amyloid, two proteins that are abnormal in people with Alzheimer's disease and are thought to start accumulating in the brain years before cognitive problems emerge. ADNI also assesses cognitive function through computer tests at home and at clinic visits, including measuring changes in ability to handle money—a warning sign of the disease.

The ADNI study has been instrumental in informing the design of clinical trials in the field of aging and dementia, with more than 500 papers published as a result of the data collected. ADNI has profoundly influenced researchers' understanding of Alzheimer's disease by identifying the earliest changes that signal disease onset and progression. Since its inception, ADNI has led to better methods for early detection of mild cognitive impairment and Alzheimer's and has contributed to physicians' and researchers' ability to detect the disease earlier and thus begin treatment at earlier stages.

The CNADC has participated in the ADNI study since its inception; the study is now a worldwide operation with sites in North America, Europe, Japan, and Australia (including 59 sites across the US) and is actively following more than 700 participants. ADNI recently started its fourth phase and is looking for new volunteers.

The initiative is currently enrolling participants; those interested must be between the ages of 55 and 90 and meet one of the following criteria:

- be cognitively healthy
- have a diagnosis of mild cognitive impairment
- have a diagnosis of early Alzheimer's disease dementia



### What is required?

- willingness and ability to undergo multiple brain scans including PET scans and an MRI (participants must not have a pacemaker, cochlear implants, etc.)
- willingness and ability to travel to Northwestern University's downtown medical campus for annual clinical and cognitive assessments, computerized testing, biomarker and genetic tests, and cerebrospinal fluid collection for up to 5 years
- a study partner with whom participant spends at least 10 hours per week

If you're interested in participating, visit [www.adni3.org](http://www.adni3.org) to complete a screening to determine initial eligibility. Please call 312-926-1851 or email [memory-research@northwestern.edu](mailto:memory-research@northwestern.edu) for more information.

Please continue to check the status of these studies on the Research and Clinical Trials section of our website, [www.brain.northwestern.edu](http://www.brain.northwestern.edu). To find out more about these research studies, contact Kristine Lipowski, MA, at 312-503-2486 or [k-lipowski@northwestern.edu](mailto:k-lipowski@northwestern.edu).

## Ten Half-Marathons in Ten States for Alzheimer's Research



You might compare Jason Boschan, also known as Run4Papa, to Superman. By the end of the year, Jason, who's already completed marathons on all seven continents, will have run 10 half-marathons in as many states on his journey to find a cure for Alzheimer's.

After finishing the 2016 Antarctica marathon, cheered on by penguins, seals, whales, and floating glaciers, Run4Papa set his 2017 goals even higher. This year's half-marathons have already taken him to Florida, Maine, Ohio, Oklahoma, Virginia, and Vermont.

Inspired by his grandfather Louis "Papa" Heyman, a pediatrician who dedicated his life to caring for children, Jason runs to raise money for dementia research. A marketer by day, Jason has been encouraged by the many people and families he's met throughout the world, many of whom have loved ones battling dementia or have lost a family member to the disease. To date, Jason has completed more than 50 races.

This year Jason is looking to help fund a state-of-the-art research facility at the CNADC. "I will continue to run races all over the world in honor of my Papa and everyone who is



battling or has lost loved ones to this vicious disease," he says. "I won't stop until a cure is found." One hundred percent of every contribution to Run4Papa funds Alzheimer's research at Northwestern.

"Alzheimer's affects people around the world," Jason says. "While I am running all over the map, my inbox is flooded with emails from inspired people wanting to be part of this challenge in their own cities. Their faces and stories coincide with my own, and I feel empowered to keep running for all of us."

To learn more, visit [Run4Papa.com](http://Run4Papa.com).

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## Continuing the Search for Dementia Prevention and Effective Treatment and Care

In 2017, the CNADC entered its 21st year of continuous funding from the National Institute on Aging. Five core areas work together to form the center: clinical; administrative; neuropathology; data management and biostatistics; and outreach, recruitment, and education.

The Clinical Core seeks to enroll and maintain a registry of people with different forms of dementia (including Alzheimer's disease, primary progressive aphasia, frontotemporal dementia, and mild cognitive impairment) as well as cognitively healthy individuals. By following participants annually, we will be able to support clinical and basic research on memory and aging.

Participants provide health and family history during annual visits, undergo neuropsychological and neurological testing, and donate blood for study. Most participants have

also agreed to brain donation at time of death to contribute to the understanding of brain changes that cause some people to develop dementia while others remain cognitively healthy. The five core areas work closely to recruit and enroll participants, assist with brain donations, support investigations of dementia and aging, and provide education about dementia to communities.

Since 1996, the Clinical Core has enrolled more than 2,000 participants, with more than 520 currently being followed. Within the last year, these amazing volunteers have helped us collaborate on 22 research studies supported by 15 grants totaling over \$2.5 million and leading to more than 20 scientific publications. The CNADC is grateful to its volunteers for their continued support and their dedication to the Clinical Core.

## SuperAging Update

The CNADC's SuperAging Project continues to grow and uncover clues on how to slow or avoid age-related cognitive decline. For about a decade, one of our longest-running studies has researched people over 80 who continue to perform at high cognitive levels as they age. As demonstrated on a variety of neuropsychological tests, these "SuperAgers" have exceptional memory ability that more closely resembles that of adults in their 50s or 60s. The study seeks to discover the biological factors that help people resist age-related cognitive decline and memory loss.

Our most recent findings showed that over an 18-month interval, normal agers lost brain cortex volume twice as fast as SuperAgers. This indicates that SuperAgers have some form of resistance to a normal older adult's rate of decline.

The SuperAging study has also seen recent personnel changes. We welcomed Beth Makowski-Woidan as our new project coordinator earlier this year, while Amanda Cook, a PhD student in Northwestern's clinical psychology program, left the CNADC to begin an internship at Emory University.



To celebrate the study's accomplishments and extend gratitude to our longitudinal research participants, we hosted a luncheon in May showcasing major research findings that would not have been possible without our many dedicated participants. To date, we have enrolled more than 70 SuperAgers (between ages 80 and 102).

We continue to recruit participants over age 80 who are actively engaged in life. To learn more, contact **Beth Makowski-Woidan** at [agingresearch@northwestern.edu](mailto:agingresearch@northwestern.edu) or 312-503-2716.

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## Arts Camp for Brain Health

The CNADC took part in the pilot Arts Camp for Brain Health program, held in June at Chicago's Old Town School of Folk Music. Northwestern was one of eight Chicago nonprofits that together created a day of arts programming for people with early-stage memory loss and diminished cognitive and neuromotor function and those who care for them.

More than 6.5 million Americans suffer from various neurodegenerative diseases. Because these conditions strike primarily in mid- to late life, the incidence is expected to soar as the population ages.

A coalition of some of the city's leading arts and health organizations presented fun and creative workshops designed to engage people with diminished neurological function in a wide range of artistic practices. The coalition was formed to dismantle silos among arts and health organizations. Joining together for a common cause for this first event, the organizations showcased their respective arts-based programs designed to counteract the stigma of neurological challenges, focusing on people's abilities rather than disabilities.



Each organization presented workshops in its unique discipline (dance, theater, music, and visual art). Northwestern highlighted two programs, Memory Ensemble and iLUMAnations, both offered at the CNADC as life enrichment programs supported through the Glen and Wendy Miller Alzheimer's Family Support Program. Nearly 100 people from around the Chicago area participated in the 50-minute workshops.

Participating organizations included the CNADC, the Art Institute of Chicago, Boomers Plus, Hubbard Street Dance Chicago, Lookingglass Theatre Company, Loyola University Museum of Art, Old Town School of Folk Music, and Video Family Biographies.

**Cognitive Neurology and Alzheimer's Disease Center**

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**Save the dates!**

**The Association for Frontotemporal  
Degeneration's 2018 Education Conference**

**Friday, April 13, 2018**

**Chicago**

[theaftd.org/newsroom/aftd-2018-education-conference](http://theaftd.org/newsroom/aftd-2018-education-conference)

**24th Annual Alzheimer Day**

**Thursday, May 10, 2018**

11:30 a.m.–4 p.m.

**The Mendelson Lecture**

Jeffrey Kaye, MD

Director of Layton Aging and Alzheimer's Disease Center; Director of Oregon Center for Aging and Technology; Professor of Neurology and Biomedical Engineering, Oregon Health & Science University

