

# CNADC NEWS

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

## Miller Family Gift to Expand Programs for Alzheimer's Patients, Families, and Caregivers

Through their \$1.25 million commitment to the Glen & Wendy Miller Alzheimer's Family Support Program at the Feinberg School of Medicine, Glen and Wendy Miller will help the Cognitive Neurology and Alzheimer's Disease Center to expand its education and support programs for individuals and families living with neurocognitive diseases. The Millers' gift will also continue their past support of the Buddy Program, establish the Miller Social Work Fellowship

Program, and help to develop an online education and support program.

"We hope that by focusing our philanthropy on not only the patients but also the caregivers and families, we will touch more people," said Glen Miller.

The Millers have been giving to the CNADC since 2008, but their involvement goes back nearly 30 years. After Wendy's mother, Marcy Raftenberg, was diagnosed with Alzheimer's disease at age 70, Wendy and her father, Mike Raftenberg, became Marcy's primary

then a member of the Alzheimer's Association's board, who now serves as research associate professor at the CNADC. In 2003 Wendy created the Family Caregiver Conference in partnership with the Alzheimer's Association.

"What a privilege it has been to work with Wendy. I am immensely grateful to have her support and that of the entire Miller family," said Morhardt. The Family Caregiver Conference tripled in size over the course of a few

years and included the largest resource fair of its kind at that time.

After the final conference was held in 2008, Wendy's involvement with

*"We can't let our memory of Wendy's mother be darkness. We want to try to turn it into something good." — Glen Miller*

caregivers. Marcy's dementia worsened over the next 14 years until she succumbed to the disease's complications in 2002.

During her struggle to cope with her mother's condition, Wendy sought help through the Chicago chapter of the Alzheimer's Association and its Family and Caregivers Support Group. There she met Darby J. Morhardt,

the CNADC grew. "We can't let our memory of Marcy be darkness," said Wendy's husband, Glen. "We want to try to turn it into something good."

The Millers' continued commitment in the form of their recent gift "will not only significantly impact quality of life for those with neurocognitive diseases and for caregiving families, but also will provide essential experiential



*Glen and Wendy Miller with their daughter Lauren (left) in 2006*

## 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.

CNADC News is funded in part by NIA grant AG13854—Alzheimer's Disease Core Center, Chicago, Illinois, and is published by the Cognitive Neurology and Alzheimer's Disease Center of Northwestern University.

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## The Northwestern Alzheimer's Disease Center: Yesterday, Today, and Tomorrow

A Message from M.-Marsel Mesulam, MD, CNADC director and Ruth Dunbar Davee Professor of Neuroscience



The Northwestern Alzheimer's Disease Center (ADC) just received an \$8.6 million award from the National Institutes of Health and the National Institute on Aging to continue and expand its work during the next five years, from 2016 to 2021. At the end of this period, our center will have had continuous funding for 25 years.

Not long after we were designated an NIH-funded ADC in 1996, we discovered that a center award

is not a permanent entitlement. Every five years, ADCs around the country must undergo competitive renewal, a high-stakes review process in which even top medical schools can lose their center designation. Our center has sailed through four competitive renewal cycles—at its 5th, 10th, 15th, and 20th birthdays—with flying colors. Twice, our score was the highest achieved by any center in that cycle. This makes me extremely proud because the praise comes from colleagues who are also potential competitors.

An important factor in our success was the establishment of the Cognitive Neurology and Alzheimer's Disease Center at the Feinberg School of Medicine in 1994. The CNADC is the parent administrative unit of the NIH-funded ADC as well as several other clinical and research programs. Having no departmental boundaries, the CNADC has been able to encourage collaboration throughout Northwestern. This is most obvious in the composition of the center's executive committee: the first associate director, Linda Van Eldik, was in the cell and molecular biology department (she now leads the University of Kentucky's ADC); her successor, John Disterhoft, is in physiology; Clinical Core leader Sandra Weintraub is located at the CNADC and has a primary appointment in psychiatry; Biostatistics Core leader Fred Rademaker is in preventive medicine; Neuropathology Core leader Eileen Bigio is in pathology; Darby Morhardt, leader of the Education Core, and Emily Rogalski, leader of the Imaging Core, have their primary appointments in the CNADC; and I have a primary appointment in the neurology department at the same time that my primary administrative responsibility is to run the CNADC. This multidepartmental coalition is at the heart of our success. Each executive committee member has held prominent positions in the national network of ADCs. Our administrator, Kevin Connolly, for example, is chair-elect of the steering committee of ADC administrators nationwide.

The CNADC has been most distinctive in its ability to attract stellar graduate students and fellows who plan to enter the field of aging and dementia research.

They thrive within our multidisciplinary environment. We have had clinicians who have joined and even conducted basic science research in our laboratories, and basic scientists who feel comfortable with clinical nomenclature and the interpretation of neuropsychological tests. These trainees will become the clinicians and researchers of the future and are likely to replicate the multidisciplinary CNADC culture in their own clinics and laboratories.

The 31 NIH-funded ADCs in the United States have three missions in common: to stimulate intramural research by providing characterized patient and tissue resources to qualified investigators; to join other NIH-funded centers around the country for large-scale collaborative studies on genetics and epidemiology; and to ensure that patients and caregivers benefit from the latest advances in the field. Our center serves all of these common missions and also engages in its own areas of research.

Over the years we have made major contributions to mainstream basic science research on Alzheimer's disease through the pioneering work of Bill Klein on the Evanston campus and the work of Linda Van Eldik, Bob Vassar, Adriana Ferreira, Changiz Geula, and the late Skip Binder on the Chicago campus.

Our center has also made unique contributions in specialized areas. One such area may be called the "emancipation of the dementia concept." Until recently, many workers in this field thought that all dementia was associated with memory loss, that dementia and Alzheimer's disease were synonymous terms, and that Alzheimer's disease came in a single flavor. Our work on primary progressive aphasia has challenged these beliefs (see PPA-related research stories beginning on page 6). For one, we showed that there are dementias where memory remains intact and the major impairment can be in word finding, visuospatial orientation, or behavioral control. We also played a leading role in identifying multiple causes of dementia, including some completely unrelated to Alzheimer's disease, such as frontotemporal dementia. This work established that Alzheimer's disease is not uniform—that it has at least five variants with distinctive clinical, anatomic, and genetic features.

Another unique area of research for our center is the SuperAging program (see story on page 15), which aims to show that Alzheimer's disease is not the common fate of all aging and that the preservation of memory into late life is a biological possibility. Our efforts to identify factors that contribute to superaging will have far-reaching implications for Alzheimer's disease prevention.

An additional special theme for our center revolves around nonpharmacologic interventions. It is no secret that dozens of recent drug trials have failed to cure or arrest Alzheimer's disease. Clearly, the process of discovering an effective medical treatment will take time. In the meantime, the patients we serve and their families remain in need of meaningful interventions. This need has motivated our focus on behavioral and psychosocial interventions that improve quality of life. One example is our Buddy Program, which has received wide publicity and is now being emulated in several ADCs around the country and abroad. Another nonpharmacologic intervention is the Communication Bridge program, which offers an Internet-based speech therapy program for patients with PPA (see story on page 7).

The absence of a definitive medical treatment for Alzheimer's disease may give the impression that the NIH-funded ADCs have not lived up to their promise and that public monies devoted to this enterprise have been wasted. This is obviously not the case. The past few years have witnessed giant advances in understanding the fundamental behavioral and biological aspects of Alzheimer's disease and related disorders. Many of these developments—such as the discovery of biomarkers that can positively diagnose Alzheimer's disease years before the onset of any memory impairment—can be credited to the collective work of NIH-funded centers.

In fact, developments in early diagnosis are now leading to clinical trials in Alzheimer's disease prevention. The CNADC is a site for one such trial, known as A4, whose purpose is to see if anti-amyloid treatment can decrease the risk of developing Alzheimer's disease (see "Clinical Trials" on page 12 for details). If A4 is successful, prevention will become a realistic prospect, analogous to heart disease prevention through control of risk factors such as cholesterol and blood pressure.

The past 20 years have been highly productive, and I look forward to the next five years with great enthusiasm. The expected fruition of the \$10 million campaign that the Feinberg School of Medicine has launched will enable our patient services, outreach activities, educational programs, and research initiatives to attain even higher levels of excellence. I look forward to working with all of you to reach these goals.



## Miller Family Gift, *continued from page 1*

learning for social workers and future doctors,” Morhardt said. “What a meaningful impact this will ultimately have on the delivery of care for this vulnerable population.”

### Partnering with the CNADC and Beyond

The CNADC’s Buddy Program, led by Morhardt, is very dear to the Miller family. In fact, the Millers provided some of the first major philanthropic support it received in 2009. Founded in 1997, the Buddy Program is an experiential learning program that addresses a lack of understanding of and appreciation for dementia-related healthcare issues in medical student education. By pairing first-year Feinberg medical students with patients, it offers mentorship opportunities for people in the early stages of Alzheimer’s disease and related disorders. The program has gained national recognition and has been successfully replicated at nine other medical schools in the United States and internationally.

“I have watched the Buddy Program grow through Darby’s efforts. We think it’s wonderful and have the utmost respect for her efforts, innovation, and passion,” said Wendy. “I wish the Buddy Program had been around when my mother was here.”

Thanks to the Millers’ generosity, the CNADC will also be able to provide opportunities for patients and families to meet with social workers for assessments and linkages to resources, education, and support. This includes three monthly support groups already offered by the CNADC. With philanthropic aid in recruiting new multidisciplinary staff members, the CNADC will be able to provide more patients and families with individualized psychosocial support.

“Under the leadership of Darby Morhardt, the CNADC has maintained a strong focus on the development of innovative interventions that enrich the quality of life for our patients and caregivers. The Buddy Program is the crown jewel of this enterprise,” said M.-Marsel Mesulam, the Ruth Dunbar Davee Professor of Neuroscience and director of the CNADC. “Wendy and Glen Miller have played a major role in the development of this program. Their new gift will ensure that the Buddy Program reaches new levels of excellence and recognition.”

In addition to their commitment to CNADC programs, the Millers are passionate about food allergy research. In



*Wendy Miller’s parents, Mike and Marcy Raftenberg, are shown here in a 1991 photo, when Marcy was in the early stages of Alzheimer’s disease. She passed away 11 years later, and Mike passed away 5 months and 2 days after Marcy.*

November 2014 they made a \$1.25 million gift to establish the Miller Family Severity Spectrum in Food Allergy Fund at the Feinberg School.

### Fifty-Six Years Together and Counting

Wendy and Glen Miller have known each other since they were 14 years old, living just three blocks apart in Chicago’s Rogers Park neighborhood. Glen mowed Wendy’s family’s lawn for years. When they became a couple in high school, friends dubbed them “Glendy.”

Glen recalls the year Wendy went away to attend the University of Wisconsin—Madison while he stayed in Chicago for school: “I remember there was a phone booth at the intersection of Howard Street and California Avenue, near my house,” he said. “I saved all my quarters to call Wendy from that phone every chance I got—even in the dead of winter.”

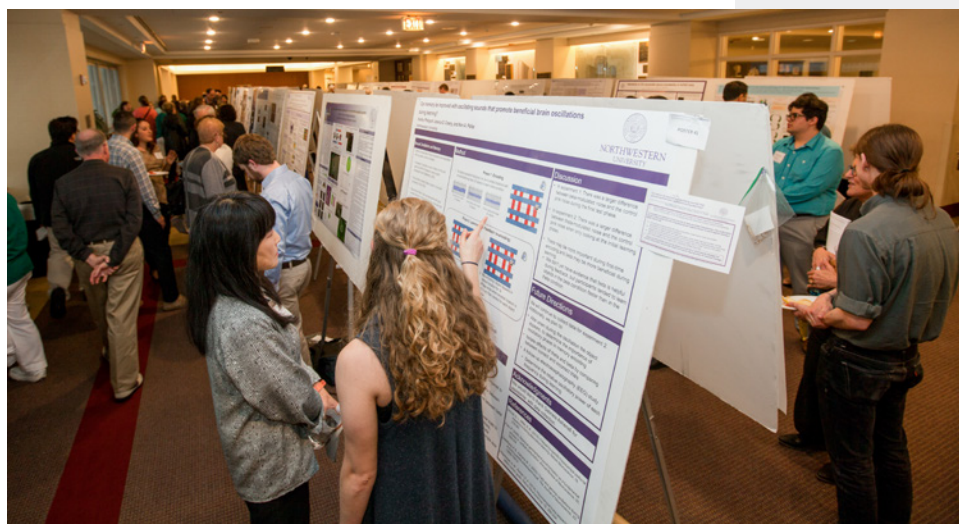
The two were married in 1967 and have built their family together in Deerfield, Illinois. All three of the Miller children are alumni of Northwestern University, and Glen taught for 15 years at the Kellogg School of Management as an adjunct professor. They have six grandchildren.

# Alzheimer Day 2016

A record 424 community members, medical professionals, scientists, researchers, and CNADC friends and family attended Alzheimer Day on May 12. Now in its 22nd year, the event showcases Northwestern research in Alzheimer's disease and related disorders.

Mendelson lecturer Kristine Yaffe, MD, professor of psychiatry, neurology, and epidemiology at the University of California, San Francisco, gave a presentation titled "Lifestyle Strategies for Prevention of Dementia." Northwestern clinicians and scientists presented 54 posters showcasing their research. The 2016 Marie and Carl Duncan Prize in Memory Research went to Ashlee Rubino for her poster "Internalized Tau<sub>45-230</sub> Aggregates Can Spread Tau Pathology and Neuronal Degeneration in Alzheimer's Disease and Related Disorders." CNADC associate director John Disterhoft, PhD, offered a tribute to the late Aryeh Routtenberg, who launched the Duncan Prize in 2008 for his notable contributions to the field of neuroscience.

The afternoon session featured the presentation "Individualizing Care: The Care Pathway Model" by CNADC's Sandra Weintraub, PhD, and Darby Morhardt, PhD. Following the presentation, a woman diagnosed with younger onset Alzheimer's disease and her two daughters—participants in the CNADC's storytelling workshop—shared their written story about the experience of living with an Alzheimer's disease diagnosis. Weintraub, Morhardt, and the storytellers were then joined by neurologist Borna Bonakdarpour, MD, and a couple living with a dementia diagnosis for a panel presentation and lively conversation with attendees.



*Clockwise from top: Jane Godfrey, member of a family affected by Alzheimer's, participates on panel; Sandra Weintraub of the CNADC gives a presentation on the care pathway model; Jane Godfrey, Judy O'Brien, and Rhiannon Mulligan share their family's story of coping with an Alzheimer's disease diagnosis; CNADC research associate professor Darby Morhardt discusses the importance of individualizing care; Mendelson Lecturer Kristine Yaffe and CNADC Advisory Board member Bob Mendelson.*

*Left: Northwestern research scientists and clinicians present their findings at the Alzheimer Day poster session.*

## Dementia Plaques Attack Language Center of Brain

Research using technology that peers into the brains of living persons with primary progressive aphasia—a rare type of language dementia that results in language loss—is providing important insights into the early stages of PPA when it is caused by a buildup of a toxic protein found in Alzheimer’s disease.

The research also offers additional insight into why this type of dementia causes people to lose the ability to express themselves and understand language.

Using a special imaging technique, Northwestern Medicine scientists have discovered that the buildup of amyloid protein is greater on the left side of the brain—the site of language processing—than on the right side in many people living with PPA.

Previously, amyloid accumulation in the brain could only be studied after a person with Alzheimer’s disease had died. This snapshot in time came after the disease had run its course and amyloid had spread throughout the brain. Now, a new technology called Amyloid PET Imaging allows researchers to study the buildup of toxic amyloid during life.

“By understanding where these proteins accumulate first and over time, we can better understand the course of the disease and where to target treatment,” said Emily Rogalski, the lead study investigator and research associate professor at Northwestern’s CNADC. The study, “Is in vivo Amyloid Distribution Asymmetric in Primary Progressive Aphasia?,” was published recently in *Annals of Neurology*.

The goal is to diagnose Alzheimer’s disease during life in order to guide treatment and identify regions to target for future drug trials.

“This new technology is very exciting for Alzheimer’s research,” said Adam Martersteck, the first author and a graduate student in Northwestern’s neuroscience program. “Not only can we tell if a person is likely or unlikely to have Alzheimer’s disease causing their PPA, but we can see where it is in the brain. By understanding what the brain looks like in the beginning stages of Alzheimer’s, we hope to be able to diagnose people earlier and with better accuracy.”

This is the first study using the Amyvid amyloid PET imaging tracer to examine and compare beta-amyloid buildup in the brain between persons with PPA and those with memory loss dementia that is more often caused by Alzheimer’s than by PPA. Both types of dementia (memory and language) can be caused by an accumulation of beta-amyloid, an abnormal toxic protein in the brain.

By using amyloid PET imaging, Northwestern scientists at the CNADC showed the toxic amyloid protein was distributed differently in people who had PPA language dementia versus memory dementia in the early stages. Researchers found there was more amyloid in the left hemisphere parietal region of people with PPA relative to those with Alzheimer’s memory dementia. This brain region is where language ability is normally processed.

Scientists scanned 32 PPA patients, and 19 of them had high amounts of amyloid and were likely to have the Alzheimer’s pathology. They were compared with 22 people who had the Alzheimer’s memory dementia. Those with the memory dementia had the same amount of amyloid on the left and right sides of the brain. —Marla Paul

*The research was funded by grant DC008552 from the National Institute on Deafness and Other Communication Disorders, grant AG13854 from the National Institute on Aging, and grant NS075075 from the National Institute of Neurological Disorders and Stroke, all of the National Institutes of Health.*

### Connect with the CNADC!

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



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## Communication Bridge: Web-Based Speech Therapy Study for Primary Progressive Aphasia

People with a diagnosis of dementia can experience changes in language as well as memory. In fact, language impairment, or aphasia, is the defining feature of the clinical syndrome primary progressive aphasia. Although there are no effective pharmacologic treatments for PPA, research suggests that speech therapy may be helpful for maximizing communication abilities and independence for activities of daily living. Unfortunately, many speech-language pathologists do not receive formal training on how to differentiate treatment strategies for patients with PPA versus those with stroke-induced aphasia, resulting in limited access to appropriate intervention for this population.

The Communication Bridge study is able to reach families who may live in remote areas or have limited access to care by delivering speech-language therapy (SLT) through a personalized, user-friendly web-based application. The CNADC's Emily Rogalski and her team worked in collaboration with the Center for Behavioral Intervention Technologies at Northwestern University to create the application, which connects participants to web-based SLT sessions, home exercises, and instructional speech therapy strategy videos. The therapy sessions are provided by speech-language pathologists at MemoryCare Corporation. The intervention sessions focus on providing individualized care and maximizing the quality of life for the family.

The study takes place over the course of six months and is completed remotely via videoconferencing. Participants receive an initial evaluation, eight SLT sessions, and evaluations at two months and six months after enrollment to determine the duration of therapy benefit. In addition to the speech-language therapy administered through the web application, participants are asked to complete testing of their language and thinking abilities as well as surveys to determine the effectiveness of SLT on functional communication ability, quality of life, and interpersonal communication.

### CNADC Participates in Speech-Language Pathologists Conference

Educating clinicians and care professionals is a primary goal of the CNADC, and education provides one avenue for sharing our research findings, disease education, and care management philosophy. In May, associate professors Darby Morhardt and Emily Rogalski, in collaboration with Becky Khayum at MemoryCare Corporation, participated in webinar presentations and Q&A chat sessions for the American Speech-Language-Hearing Association conference "Maximizing Functional Outcomes for Patients with Dementia." More than 515 attendees participated in the conference. Interest was so high that organizers plan to repeat the online conference before the end of the year.

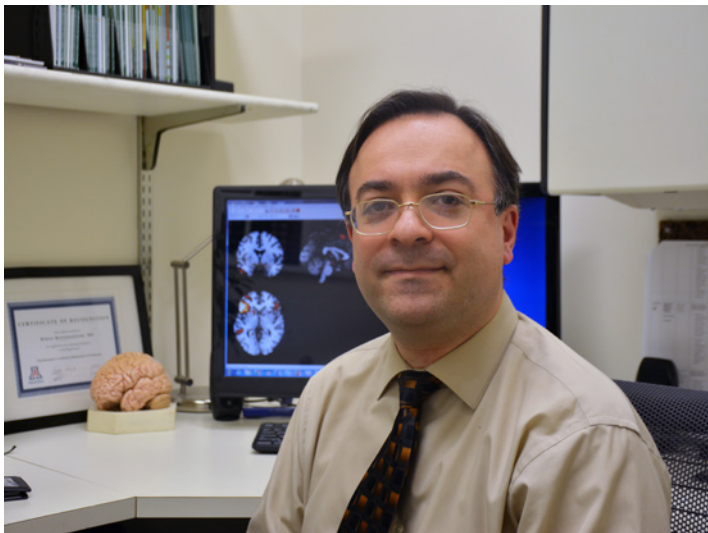
Over the past three years the Communication Bridge study has enrolled more than 40 participants. Initial results are promising and have been presented at national and international conferences. The study has received funding from the Run4Papa campaign, the Alzheimer's Association, and the Association for Frontotemporal Degeneration. Recently, the Communication Bridge study has received two grants, one from the Illinois Department of Health and the other from the Advancing Research and Treatment for Frontotemporal Lobar Degeneration Consortium. These grants will allow us to continue to enroll participants in the study.

If you are interested in more information, please contact study coordinator Marie Saxon at 312-503-4012 or [communicationbridge@northwestern.edu](mailto:communicationbridge@northwestern.edu).

## Neurologist Probes Riddle of Language Using MRI Data

Borna Bonakdarpour, MD, is interested in what happens in the brain when words seem to get stuck on the tip of the tongue. He also explores agrammatism, a condition where people maintain word comprehension but are unable to speak in a grammatically correct way.

Using functional magnetic resonance imaging (fMRI), the physician-scientist studies the brain's language network in patients who have suffered a stroke or who are afflicted by primary progressive aphasia (PPA). Both illnesses impede the normal neural pathways that words take. But neurons can fight back, as Bonakdarpour explains, because when signals



take a wrong turn, they can often be rerouted, relying on healthy parts of the brain to reach their final destination.

“The brain is an accommodating organ. When something goes wrong, it has the potential to try to regain function,” says Bonakdarpour, who joined the CNADC as the Florane and Jerome Rosenstone Fellow in 2008. “One of our goals is to design interventions—pharmacological or otherwise—that help the language network reconnect around an injured area to once again communicate with less impediment.”

More than a decade ago, Bonakdarpour was among the first Northwestern researchers to use fMRI to identify brain regions that are important in language production. That research team was able to show how aphasia disrupts such regions, producing difficulties in speaking, comprehending, reading, and writing language without affecting intelligence. Bonakdarpour explores language processing using imagery

and data collected from research participants who complete several tasks—word identification, for instance—while inside an MRI scanner. Brain activity is measured by detecting changes associated with oxygenated blood flow. The technique is currently used only in a research capacity, though Bonakdarpour believes it will eventually reach the clinic.

One of Bonakdarpour's earliest neuroimaging studies at Northwestern involved using music to help retrain neurons to connect in a meaningful way. He used CT scanning—a collection of x-ray images—to show that nonpharmacological intervention, which took advantage of the overlapping brain networks for language and music, could improve communication in patients with stroke-induced aphasia.

More recently, Bonakdarpour has worked with neurology faculty member Robert Hurley and CNADC director M.-Marsel Mesulam to define important nodes of the language network in healthy people by using resting-state fMRI.

Bonakdarpour has also used this tool to show how aphasia disrupts the language network in PPA patients.

“Even at rest, the areas of the brain that work together have a connectivity that can be seen using this newer technique,” says Bonakdarpour. “Using resting-state fMRI, we saw how the front and back portions of the language network interact and how these are disrupted in individuals with PPA.”

Based on their findings, Bonakdarpour and colleagues proposed a new resting-state fMRI model for language processing. The researchers separated the language network into three nodes and two streams. Instead of relying on the long-held theory that the back part of the brain manages language comprehension and the front part deals with language production, the investigators revealed a new model. They showed how disruption of the upper stream in PPA is related to sentence production, while disruption in the lower stream impacts naming and word-level processing.

“By better understanding the language network and increasing the functionality of fMRI, we can better design and monitor treatments to make a real impact for patients,” says Bonakdarpour. “PPA has no cure, but we hope to isolate the brain regions that are correlated with the language dysfunction and then develop a treatment that stymies the disease.”  
—Roger Anderson



## PPA Research Progress at a Glance

The CNADC continued to expand the impact of its primary progressive aphasia research programs as the center's two National Institutes of Health-funded studies—"MRI, Anatomy, and Progression in PPA" and "Language in PPA"—entered their 5th and 10th years, respectively. In the past year alone, with the help of supporters and a dedicated group of more than 150 research participants, the CNADC accomplished the following:

- **Redefined how language comprehension is seen in the brain.**  
By mapping brain regions to comprehension deficits in PPA patients, we have been able to show that single words and sentences are processed in distinct brain regions. This important finding will help guide scientists to more precise targets for future therapeutics.
- **Applied an innovative eye-tracking method to prove that semantic variant PPA (PPA-S) is more complex than previously shown.**  
By presenting PPA-S patients pictures of various objects on a screen while tracking their eye movements, we were able to illustrate how word meaning and knowledge begin to blend within a category in a hierarchal fashion rather than being altered individually.
- **Used resting-state functional MRI to illuminate brain changes that were invisible with other imaging methods.** This unique technique focuses on measuring blood-flow changes of patients while they are resting in order to better understand how different nodes of the brain interact with each other. This procedure not only enhances our understanding of the language network but also has the potential to change diagnostic procedures used for PPA.
- **Utilized PET imaging technology to show contrasting patterns of amyloid-beta protein accumulation in the brains of those with PPA versus those with amnesic dementias such as Alzheimer's disease.** This research highlighted that amyloid-beta was disproportionately affecting the left side of the brain in PPA patients, helping us get at the root of understanding why PPA is affecting language before other areas of brain functioning (see story on page 6).
- **Became the first department in the Feinberg School of Medicine to scan patients using the new AV-1451 PET tracer.** This novel agent is being used to map deposits of the abnormal tau protein in patients with PPA. Complementing our study of amyloid-beta, these scans will contribute important knowledge about disease mechanisms in PPA.

In the coming year we will continue to apply state-of-the-art techniques to learn about primary progressive aphasia from all possible angles. For information on the PPA research programs or to participate, please contact coordinator Ben Rader at 312-908-9681 or [benjamin.rader@northwestern.edu](mailto:benjamin.rader@northwestern.edu).

## Promoting Brain Health— with a Dash of Humor

In June the CNADC partnered with the US Department of Health and Human Services' Administration for Community Living to bring the Laugh Lines storytelling event series to Chicago.

People from across the Chicago area gathered on June 25 for "Laugh Lines: A Storytelling Event about the Experience of Getting Older," hosted by CBS2 Chicago's weekday sports anchor, Ryan Baker. The event drew nearly 100 people, mostly older Chicago-area natives, who listened as six older adults—all amateur storytellers—engaged in a friendly competition by sharing entertaining stories about various aspects of aging. Olga Loya, an award-winning professional storyteller from Stagebridge, the nation's oldest theater company of older adults, based in Oakland, California, introduced and followed the competitive portion with two funny stories of her own.

The CNADC's Lauren Dowden served on the event's judging panel and helped select Omiyale' DuPart, active member of the Chicago Association of Black Storytellers, as the Laugh Lines Chicago winner.

The Laugh Lines storytelling event series is sponsored by What Is Brain Health?, a national campaign launched by the Administration for Community Living in 2015. The campaign helps raise awareness about brain health while empowering older adults to make the most of their brains as they age. The event combines entertainment and education, using storytelling to teach older adults how they can help keep their brains healthy. Visit [www.brainhealth.gov](http://www.brainhealth.gov) to learn more.

## Research Studies for Mild Cognitive Impairment

### What is mild cognitive impairment?

Mild cognitive impairment is considered a transitional stage between “normal” or expected age-related cognitive decline and more significant decline that occurs with dementia. MCI is defined by difficulties with memory, language, attention, or judgment, among other thinking abilities. But these problems are not severe enough to impact activities of daily living, such as work responsibilities or hobbies. Nor do family and acquaintances notice changes in daily life. When MCI is characterized by a primary memory impairment, it is known as amnesic MCI or aMCI. For example, a person with aMCI may begin to misplace important belongings, may forget recent events, or may forget conversations, even within a short amount of time.

### Why is it important to study MCI?

Persons who have been clinically diagnosed with MCI are at an increased risk of developing Alzheimer’s disease or other causes of dementia; therefore, clinicians recommend that they be evaluated regularly to determine if cognitive symptoms are improving, staying the same, or progressively worsening over the course of a year. Researchers study MCI in order to develop diagnostic tools to help predict the underlying causes of dementing illnesses like Alzheimer’s disease. A major research goal is to develop interventions and therapies that aim to prevent cognitive decline and dementia. Studying MCI provides the opportunity to investigate

the first stages of dementing illnesses, allowing the possibility for early intervention.

### What studies on MCI are being done at Northwestern?

Northwestern Alzheimer’s Disease Center supports MCI studies in several ways. People who have been clinically diagnosed with MCI are enrolled in our Clinical Core, where they are followed annually. The Clinical Core is a registry that collects demographics, health history, and neurological information from participants and administers a research neuropsychological test battery. These data are used to support researchers who are studying MCI at Northwestern and are anonymously shared with the National Alzheimer Coordinating Center to support research studies throughout the country.

MCI participants at Northwestern also are given the opportunity to participate in additional studies by approved researchers to contribute to memory and aging research. From time to time, they are notified of studies for which they are eligible and invited to participate. For example, one study utilizing Core participants with MCI is an investigation of the effect of sounds played during sleep to see if this treatment can improve memory.

### How can I learn more or participate?

If you are interested in learning more about or participating in MCI studies at the CNADC, please visit our website at [www.brain.northwestern.edu](http://www.brain.northwestern.edu) or call us at 312-695-1851.

## Participants Needed for Frontotemporal Dementia Research Project

### What is ARTFL?

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. Funded by the National Institutes of Health and the National Institute of Neurological Disorders and Stroke, Northwestern’s CNADC is one of 14 ARTFL sites throughout Canada and the United States that will be enrolling FTLD patients for on-site evaluations. The goal of the study is to build a clinical research consortium to support the development of new therapies and diagnostic tools for combating dementia associated with FTLD.

### Why is it important?

Frontotemporal lobar degeneration refers to a collection of rare neurodegenerative diseases that gradually affect one’s ability to behave appropriately, empathize with others, learn, reason, make judgments, communicate, and carry out daily activities. It includes four main clinical conditions: behavioral variant frontotemporal dementia, primary progressive aphasia, corticobasal degeneration, and progressive supranuclear palsy. Some people with amyotrophic lateral sclerosis (ALS) also have dementia of the FTLD type. Onset for these diseases tends to occur before age 65, and while there is currently no treatment or cure for FTLD, some medications and lifestyle changes can help

## Spotlight on the Clinical Core

relieve the symptoms. ARTFL aims to establish a registry of individuals with these disorders who will be ready to enter a clinical trial once an appropriate treatment has been identified.

### **What is involved in the ARTFL study?**

The on-site ARTFL visits will include cognitive testing, medical exams, the collection of medical and family history, and the donation of a blood sample. Healthy family members of patients with genetic causes of FTL, or a strong family history, may also be enrolled. The collective sites will use the gathered information to discover new biomarkers for disease activity, standardize diagnostic criteria, and identify a large group of potential participants for clinical trials of new targeted therapies.

### **How can I learn more or participate?**

If you are interested in learning more about or participating in ARTFL, please visit [www.brain.northwestern.edu/research/studies/ARTFL.html](http://www.brain.northwestern.edu/research/studies/ARTFL.html) or [www.rarediseasesnetwork.org/cms/artfl/About-Us](http://www.rarediseasesnetwork.org/cms/artfl/About-Us).

This past year the Northwestern Alzheimer's Disease Center entered its 21st year of continuous funding from the National Institute on Aging. Five "cores" work together to comprise the Northwestern ADC: Clinical; Administrative; Neuropathology; Data Management and Biostatistics; and Outreach, Recruitment, and Education.

The Clinical Core seeks to enroll and maintain a registry of cognitively healthy individuals as well as persons with different forms of dementia (e.g., Alzheimer's disease, primary progressive aphasia, frontotemporal dementia, mild cognitive impairment). By following participants annually—through the normal aging process or throughout the course of their disease—we are able to comprehensively define research participants to support clinical and basic research on memory and aging. Participants are asked to provide health and family history during annual visits, undergo neuropsychological and neurological testing, and donate blood for studies on brain aging and dementia. The majority of participants have also agreed to brain donation at the time of death to contribute to the understanding of why some people develop dementia while others remain cognitively healthy throughout their lives. The five cores work closely together to recruit and enroll participants, assist with brain donations, support investigations of dementia and aging, and provide education to communities about dementia and how to care for and support individuals and families who are navigating a dementia diagnosis.

The Clinical Core has enrolled more than 2,000 comprehensively defined participants since 1996, with more than 520 participants currently being followed. In the last year alone, volunteers helped us collaborate on 22 individual research studies supported by 15 grants totaling more than \$2.5 million and leading to more than 20 scientific publications. Research participants are recruited by our collaborators to address questions that range from what protects the brain from Alzheimer's disease (SuperAging), research to try to

prevent Alzheimer's in individuals who may be at elevated risk for the disease (A4), and studies providing treatments for individuals with mild cognitive impairment (Sleep Sounds Study, transcranial magnetic stimulation study). Please visit our website—[www.brain.northwestern.edu](http://www.brain.northwestern.edu)—for more information about these studies.

### **A4 Study Featured on WTTW**

CNADC Clinical Core director Sandra Weintraub spoke to local PBS television station WTTW's *Chicago Tonight* about the groundbreaking Anti-Amyloid Treatment in Asymptomatic Alzheimer's (A4) study conducted at the center.

"The study tests a drug or placebo on individuals who are at greater risk because of elevated amyloid," Weintraub said, "in the hopes of reducing levels of amyloid in the brain or even preventing it from accumulating in an attempt to prevent the onset of cognitive decline."

See the A4 article on page 12 to learn more about this clinical trial.

## CLINICAL TRIALS

The Alzheimer's Therapeutic Research Institute group is conducting the following studies through grants from the National Institute on Aging:

### **NEW**

#### **Anti-Amyloid Treatment in Asymptomatic Alzheimer's Disease (A4)**

It is well known that the biological changes in the brain that cause dementia associated with Alzheimer's disease develop many years before memory loss becomes apparent. There are now methods for detecting these changes with the use of a test called an amyloid PET scan. The A4 study is a new "secondary prevention" study to treat individuals aged 65 to 85 at risk for developing Alzheimer's disease as determined by evidence of amyloid accumulation on brain PET scans.

Adults aged 65 and older with normal cognitive test scores will be screened with PET amyloid imaging. Those with elevated amyloid who also meet other stringent study criteria will be eligible to enroll in the trial. Enrolled participants will be treated for three years with an anti-amyloid antibody (similar to a vaccine) or with placebo.

Northwestern University is one of more than 65 sites selected to participate in this groundbreaking study. Enrollment is currently open and will continue into early 2017. Because of the lengthy screening period and rigorous study schedule, study staff will be conducting prescreenings over the telephone to assess for initial eligibility.

#### **Study of Nasal Insulin to Fight Forgetfulness (SNIFF)**

The SNIFF study will evaluate whether a type of insulin improves memory when administered as a nasal spray to adults with amnesic mild cognitive impairment or early Alzheimer's disease. The study will also look at the effect of insulin on brain structure and function, cerebrospinal fluid biomarkers, and blood biomarkers. Insulin resistance, reduced cerebrospinal fluid insulin levels, and reduced brain insulin signals have been found in persons with a diagnosis of AD dementia, suggesting that a therapy aimed at correcting these deficiencies may be beneficial.

Adults between 55 and 85 years of age with a diagnosis of amnesic mild cognitive impairment (aMCI) or early Alzheimer's disease can be considered for participation. Eligible participants will be given a nasal spray device with either insulin or placebo. They will be randomly assigned to the treatment or the placebo group for 12 months, followed by 6 months in which all participants will receive insulin. Participants are required to make four visits over the 12-month treatment phase. Enrollment is expected to continue into 2017.

### **ONGOING**

#### **Alzheimer's Disease Neuroimaging Initiative**

The Feinberg School of Medicine completed recruitment for the first national study to detect Alzheimer's disease in older people before they begin to have significant memory loss. The CNADC is one of 53 National Institute on Aging sites participating in the study, an expansion of the National Institutes of Health's Alzheimer's Disease Neuroimaging Initiative. The next phase of the ADNI study (ADNI3) is projected to begin in late 2016 or early 2017 and will enroll participants with no memory impairment, those with mild cognitive impairment, and those diagnosed with early-to-mild Alzheimer's disease.

*The Alzheimer's Disease Neuroimaging Initiative is funded by the National Institutes of Health; the Food and Drug Administration; pharmaceutical, imaging, and clinical trial management companies; nonprofit organizations, including the Alzheimer's Association and the Alzheimer's Drug Discovery Foundation; and private donors.*

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 at 312-503-2486 or [k-lipowski@northwestern.edu](mailto:k-lipowski@northwestern.edu).

## Effort to Care for Korean Americans Gains Momentum

The KARE partnership between Chicago's Korean American Community Services and the CNADC grew stronger in 2016 when the KARE project team received a Retirement Research Foundation service grant to educate Korean Americans about Alzheimer's disease and other dementias.

Korean Americans hold a range of attitudes toward dementia, particularly a sense of stigma and shame rooted in misunderstandings about the cause. Korean American Senior Housing communities expressed the need for Alzheimer's disease education due to stigmatization and marginalization, the rising number of individuals in residences with cognitive impairment, and questions about how to best support them and the larger community.

To date, four Korean American Senior Housing buildings and two Korean American churches that host older adult courses have received education on brain health and the basics of Alzheimer's disease.

The curriculum for these programs is the *Brain Health Resource*, a presentation toolkit designed by scientists and educators at three Health and Human Services agencies. Translated and delivered in Korean by KARE program manager Jimyong Kim, the 60-minute presentations cover good health and the normal aging brain, threats to brain health, and strategies for communicating with people with cognitive decline. Each presentation is followed by an interpreted Q&A session with CNADC faculty member Darby Morhardt. To date, more than 200 older adults have taken part in the presentations.

Kim is developing a bilingual booklet summarizing the presentation and incorporating salient information from the focus groups and Q&A sessions.

The sessions will continue for the remainder of the year. It is expected that this effort will raise awareness of stigma, brain health, and cognitive impairment for older Korean Americans and add an essential layer to designing a model of adequate care. The hope is to break the link between dementia and stigma and to provide families with resources to care for those living with Alzheimer's disease and other dementias.

For more information regarding KARE, contact **Darby Morhardt** at [d-morhardt@northwestern.edu](mailto:d-morhardt@northwestern.edu) or **Jimyong Kim** at [jkim01@kacschicago.org](mailto:jkim01@kacschicago.org).



*KARE project participants attend a brain health program delivered in Korean.*

## Project Raises Alzheimer Awareness in the African American Community

According to a 2016 report by the Alzheimer's Association, African Americans are twice as likely to develop Alzheimer's disease as others. In light of this disparity, it is important that African Americans are well represented in the increasing number of research studies now in development.

In July 2015 the CNADC cosponsored an event featuring two performances of Garrett Davis's stage play *Forget Me Not* at Chicago's DuSable Museum of African American History. The play centered around an older African American man experiencing early symptoms of Alzheimer's disease and how his family and friends come together to support him. The play delved into the complex issues that many African American families face when dealing with a dementia diagnosis with humor and compassion.

More than 900 people attended the event. After each performance, the audience was invited to take part in a panel discussion about Alzheimer's disease and learn more about the CNADC's A4 clinical trial. Featured panelists included CNADC Clinical Core director Sandra Weintraub and *Forget Me Not* creator and star Garrett Davis.

The response from attendees was overwhelmingly positive, and more than a year later the CNADC continues to hear about the play's lasting impression on those who attended. Such events will continue to play an important part in national efforts to include historically underrepresented racial and ethnic groups in research on Alzheimer's disease.

## Run4Papa Campaign in Antarctica



Jason Boschan is a veteran of nine marathons and has experienced plenty in his racing days. He climbed up and down 5,164 steps for the Great Wall of China Marathon, was stopped at mile 25.8 of the 2013 Boston Marathon

due to the bombing, ran in ankle-deep sand on an open animal reserve in South Africa, withstood a monsoon in Rio, and trekked through the red clay of the Australian Outback. However, nothing could ever prepare him for the nervous energy of the Antarctica Marathon this past March.

“The training was nearly impossible,” Boschan said. “The incredibly strong winds, plunging temperatures, and 11 layers of clothing made this the most unique and thrilling running experience. I’m certain that I’ll never come across floating icebergs or families of penguins on any future runs. When you come this far, the only acceptable result is to finish.”

This November, Boschan and the Run4Papa campaign are headed to Athens, Greece, to finish the journey with another marathon on a seventh continent. In a little over five years, Boschan has run countless races on behalf of those



with Alzheimer’s disease and related disorders, raising over \$180,000 to advance research, education, and patient care at Northwestern Medicine. He has made his way around the world, running to honor his late grandfather, Louis “Papa” Heyman (pictured above with Boschan), who passed away from dementia in 2013.

“Jason’s passion for advancing research is inspiring to our patients and researchers,” said Kevin Connolly, CNADC administrator. “He has sacrificed so much for this cause and honored his grandfather with a very moving tribute.”

To follow Boschan’s journey or make a donation, please visit [www.run4papa.com](http://www.run4papa.com). All proceeds go directly to research, education, and patient care at the CNADC.

## SEED: Support and Education for Early Dementia

Those with a new diagnosis of dementia and their families can find resources and support in SEED—Support and Education for Early Dementia.

The eight-week CNADC program, launched in fall 2015, is facilitated by social workers and assisted by two people with an Alzheimer’s disease diagnosis and their spouses who volunteer as mentors. Their insight and guidance to group members has helped shape the program.

SEED’s structure is based on previous models and input from mentors. The first half of each two-hour session is devoted to education on a designated topic, featuring presentations by experts in the field. Topics include the basics of dementia, compensatory strategies that address cognitive changes, financial and legal considerations, the effect of the illness on family relationships, disclosing the diagnosis to others, community resources and quality of life interventions, and drug treatments and research opportunities.

The sessions’s second hour provides members the opportunity to participate in a support group. Family members and individuals with a diagnosis meet separately to get to know one another and share their experiences navigating a new diagnosis. These groups are facilitated by clinical social workers along with mentors who offer insight and support to participants.

Twenty-one people between the ages of 35 and 82 from the Chicago area and northern Indiana have participated in two eight-week SEED program sessions. Participants have included spouses, parents, children, siblings, and people with a diagnosis of Alzheimer’s disease or a related disorder.

SEED participants complete a short questionnaire regarding their experience after each session, with the results used to improve future sessions. The CNADC SEED program is currently offered twice a year. For more information, please contact Lauren Dowden at [lauren.dowden1@northwestern.edu](mailto:lauren.dowden1@northwestern.edu).

## CNADC's SuperAging Study Is Aging Well

During the past nine years, Northwestern's SuperAging Project has been researching people over the age of 80 who continue to perform at high levels cognitively as they grow older. As demonstrated on a variety of neuropsychological tests, these "superagers" have exceptional memory ability that more closely resembles that of adults 20 to 30 years younger. The study seeks to find out the biological factors that help people resist age-related cognitive decline and memory loss.

One of the CNADC's longest-running studies, the SuperAging Project has grown steadily and is uncovering clues to how to slow or avoid age-related cognitive decline. Neuroimaging has shown that superagers exhibit a thicker cortex in the brain compared to cognitively average age-matched controls and healthy 50- to 60-year-olds. Superagers also tend to maintain outstanding cognitive performance on tests that measure episodic memory.

The study's unique multifaceted approach has provided insights into the genetic and anatomic makeup behind superaging. For example, genetic testing has revealed that superagers have a lower frequency of the E4 allele of the apolipoprotein gene, a risk factor for Alzheimer's disease. Recent findings from superagers who have donated their brains to the study show unusually low amounts of Alzheimer pathology. Superaging brains also have a higher density of von Economo neurons that are associated with social intelligence.

The SuperAging Project has produced five scientific publications and continues to receive international media attention. To date, the study has enrolled more than 70 superagers (ages 80 to 102) and continues to recruit participants over the age of 80 who are actively engaged in life.

To learn more about the SuperAging Project, contact Emmaleigh Loyer at [agingresearch@northwestern.edu](mailto:agingresearch@northwestern.edu) or 312-503-2716.

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## Don't Look Away: Using Storytelling to Give Voice, Change Perceptions

The CNADC developed a storytelling pilot workshop with two couples (individuals with Alzheimer's disease and their spouses) to assist in the cocreation of a story that they shared at the 2014 Alzheimer's Day. The storytellers' reflections revealed how the process of reminiscing to create their story allowed the couple to spend time together in a way that helped maintain their "couplehood" as husband and wife, as opposed to being identified as caregiver and patient.

The CNADC received a Northwestern University Alumnae Grant in 2015 to research the storytelling program. The project aims to explore the impact of the dyadic storytelling workshop on the couple's relationship and communication. Participants meet for eight weeks for 90 minutes. Using in-class writing, at-home assignments, and group feedback, couples cocreate their shared story. The stories are presented in the final session and eventually to the public. Eighteen people (nine dyads) from the Chicago area, Indiana, and Michigan have participated in the workshop. The couples have been spouses, siblings, parents, and children, ranging in age from 34 to 80. Preliminary findings on the impact of the workshop include increased connection between the couple



*Storytellers Ben and Robyn Ferguson*

as they reflect on how they overcome difficult times, build on historical strengths, and develop resilience.

The storytelling couples have collectively shared their stories with more than 1,000 people in the Chicago area, including medical and other health professionals, students, scientists, and community members. Feedback from audience members reflects a deeper understanding of the lived experience of a family living with Alzheimer's disease and other dementias.

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

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**Popular Museum-Going Program  
Featured on WTTW**

ilLUMAnations, the art-viewing program for people with cognitive impairment and their care partners, was recently featured on WTTW's *Chicago Tonight*. A partnership between the CNADC and Loyola University Museum of Art, the program originated in 2013 and offers participants the chance to view current LUMA exhibits and the permanent collection. Trained docents lead tours of the artwork and small group discussions on days when the museum is closed. The popular program has grown from 5 to 10 sessions per year.

"Looking at the artwork, everyone is engaged," one family member said. "And the docents are good about pulling out what [patients] think and how the artwork makes them feel."

For more information about ilLUMAnations, please contact Lauren Dowden at [lauren.dowden1@northwestern.edu](mailto:lauren.dowden1@northwestern.edu).



*ilLUMAnations participants tour the Loyola University Museum of Art.*