

CNADC NEWS

Produced by the COGNITIVE NEUROLOGY

AND ALZHEIMER'S DISEASE CENTER



SuperAger study participants Grayce Papp (left) and Evelyn Finnegan. Photo courtesy of Al Podgorski, *Chicago Sun-Times*.

Researchers have long chronicled what goes wrong in the brains of older people with dementia. Emily Rogalski, an assistant research professor at the CNADC, wondered what goes right in the brains of elderly people who still have terrific memory. Rogalski's newly published study has for the first time identified an elite group of people age 80 and older whose memories are as sharp as people 20 to 30 years younger. On three-dimensional MRI scans, the brains of these so-called cognitive superagers looked as if they were young—and one brain region was even larger—compared with the brains of the study's middle-aged participants.

Rogalski was astounded by the vitality of a superager's cortex—the brain's outer layer, important for memory, attention, and other thinking abilities. The cortexes of the superagers were much thicker than those of the group of normal people over age 80, whose cortexes showed significant

STUDYING THE SECRETS OF SUPERAGER BRAINS

thinning, and closely resembled the cortex size of participants ages 50 to 65.

"These findings are remarkable, given that gray-matter or brain-cell loss is a common part of normal aging," says Rogalski, the principal study investigator and senior author of the paper, published in the online edition of the *Journal of the International Neuropsychological Society*.

Rogalski hopes to unlock the secrets of what protects some older people from the deterioration of memory and atrophy of brain cells that accompany aging. Her discoveries may be applied to protect others from memory loss or even Alzheimer's disease. "Looking at a really healthy older brain may inform our strategies for improving quality of life for the elderly and for combatting Alzheimer's disease," she says.

Rogalski gets a sense of how many brain cells are left by measuring the thickness of the cortex, where neurons (brain cells) reside. "We can't actually count them, but the thickness of the outer cortex of the brain provides an indirect measure of the health of the brain," she says. "A thicker cortex suggests a greater number of neurons."

Another region deep in the brain, the anterior cingulate, was actually thicker in the SuperAger study participants than in the study's 50- to 65-year-olds. "This is pretty incredible," says Rogalski.

"This region is important for attention.

Attention supports memory. Perhaps the superagers have really keen attention and that supports their exceptional memories."

To be defined as a superager, participants needed to score at or above the norm of the 50- to 65-year-olds on memory screenings. Only 10 percent of study volunteers who thought they had outstanding memories met those criteria. "These are a special group of people," says Rogalski.

Rogalski's Chicago-area study involved 12 superagers, 10 normally aging participants (average age 83.1), and 14 middle-aged participants (average age 57.9); there were no significant differences in education among the groups. She viewed MRI scans of their brains and screened their memory and other cognitive abilities.

Most of the SuperAger study participants say they plan to donate their brains to the ongoing research. "By studying their brains," says Rogalski, "we can link the attributes of the living person to the underlying cellular features."

The study's Northwestern coauthors include M.-Marsel Mesulam, Sandra Weintraub, and former graduate student Theresa Harrison. The project was supported by a grant from the Davee Foundation and the National Institute on Aging of the National Institutes of Health.



M.-Marsel Mesulam

Dear Friends and Colleagues,

Welcome to the 2012 *CNADC News*. This has been another productive year for the CNADC, where dozens of dedicated staff, clinicians, and scientists interact to fulfill research and patient-care goals. This newsletter highlights just a few notable developments of the last year. I hope that you will find the contents of interest and will feel free to contact me with comments or questions.

Our SuperAging Project, described on page 1, recently generated unprecedented media coverage. Project investigators identified people above the age of 80 with unusually sharp memory abilities who have avoided normal age-related brain shrinkage. The next research phase is to identify the factors that promote superaging, looking for clues to preventing memory decline in average aging and perhaps in Alzheimer's disease (see page 11).

This year the CNADC was awarded two major research grants by the National Institutes of Health for research on primary progressive aphasia (see page 11). As a national referral center for PPA, the CNADC currently serves patients and families from more than 30 states. In the past few months CNADC investigators published major research papers on the early diagnosis and multiple causes of PPA. The CNADC focus on PPA is part of our comprehensive clinical, neurobiological, psychosocial, and educational programs on frontotemporal degenerations.

The current year has been particularly fruitful for the Care Pathway Program, which customizes interventions to individual patients' strengths and weaknesses. With Alzheimer's disease, PPA, and frontotemporal degeneration being diagnosed at increasingly earlier stages, when the level of disability may be minimal and when many years of active life may lie ahead, life enrichment interventions such as the Care Pathway and Buddy Programs have optimized the quality of life for our patients and families.

I thank Craig Grannon, who has completed his term as chair of the CNADC Community Advisory Board, for his wise counsel and generous support. I am delighted that Craig remains on the board to give us much-appreciated guidance. I am pleased to announce that Terry Chapman has assumed the board chairmanship, continuing his family's tradition of close ties with the CNADC. With Craig and Terry, the advisory board's executive committee also includes David Moscow as chair-elect. The CNADC is grateful to all the board members for their dedication to the goals of excellence in patient care and research at Northwestern University.

I also thank our patients and families who have volunteered in the CNADC's research, advocacy, and community education programs. Your participation has contributed to advancing science, enhancing public awareness, and influencing public policy. We face many formidable challenges in our fight against Alzheimer's disease, PPA, FTD, and related disorders. You are part of the team, and your dedication to this cause is very much appreciated.

With warm regards,

M.-Marsel Mesulam, MD

CNADC Director and Ruth Dunbar Davee Professor of Neuroscience

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 30 Alzheimer's Disease Centers funded by the National Institute on Aging, National Institutes of Health.

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CARE PATHWAY PROGRAM ADDRESSES INDIVIDUAL NEEDS

Extensive research shows that dementias are not uniform; each patient should be characterized individually to receive the most appropriate interventions. The “care pathway” approach addresses unique needs by profiling neuropsychological strengths and weaknesses. By viewing the symptoms affecting the person’s daily life, clinicians can provide appropriate strategies for coping.

During the past 16 months 152 patients have been seen by the Care Pathway Program at the Neurobehavior and Memory Clinic. This chart shows the distribution of their dominant cognitive symptoms, categorized into four care pathways or neurocognitive profiles: memory loss, visuospatial/perceptual problems, language decline, and behavioral/emotional changes.

Care pathway	Number of patients	Percentage of patients
Memory deficits	74	49%
Language decline	55	35%
Behavioral/emotional changes	17	11%
Visuospatial problems	8	5%

Based on the dominant cognitive symptom, the care pathway coordinator works with patients and families to identify appropriate recommendations and strategies to improve quality of life. The following chart shows common recommendations within each care pathway.

Care pathway	Percent receiving recommendation	Recommendation
Memory	78%	Staying active through modification of activities
	27%	Occupational and speech therapy referrals
	16%	Interpersonal communication tips
	12%	Memory compensation techniques
Behavior	88%	Educational-based suggestions for interaction
	70%	Support for caregiver; accessing additional care resources
	47%	Safety devices and strategies
Language	52%	Interpersonal and environmental communication tips
	45%	Speech therapy referrals
	30%	Communication augmentation devices
Visuospatial	100%	Suggestions for environmental changes
	100%	Low-vision services
	100%	Occupational therapy referrals

Feedback surveys help clinicians understand whether the care pathway model meets the needs of patients. Completed surveys revealed that 78 percent of respondents agreed or strongly agreed that the strategies help them better manage the disease; 84 percent agreed or strongly agreed that they plan to implement some of the strategies; and 74 percent agreed or strongly agreed that the care pathway service will improve quality of life.

This model of care will continue to be evaluated, and a manual about the approach will soon be available for other clinicians. If you would like to learn more about the care pathway model, please call **Jaimie Robinson** at **312-695-9627**.

RESEARCH

Study Focuses on Brain Workouts

A team of researchers and clinicians led by CNADC neuropsychologist Beth Borosh is studying how education about brain wellness strategies and cognitively stimulating activities can improve quality of life in people diagnosed with mild cognitive impairment.

As part of the study, the brain wellness workshop CHANGE—Cognitive Health and Neurobehavior Group Education—is aiming to optimize memory and thinking and improve quality of life in those with mild cognitive impairment.

Over six weekly sessions CHANGE educates participants about five components of brain health: sleep, mood, nutrition, physical activity, and social engagement. The workshop also includes cognitive training. Each session includes discussion of homework assignments and introduces a different game to exercise the mind.



Although more research is needed to fully understand the link between mental exercise and brain health, healthcare professionals are gaining a better understanding of risk factors for cognitive decline, and many researchers recommend daily “brain workouts” to optimize memory and thinking. Games, puzzles, and computerized software programs are among the ways to use the brain in active ways. Other options are taking a course in an unfamiliar subject, taking on a project that involves design and planning (e.g., gardening, quilting), and getting in the habit of learning new things (e.g., recipes, driving routes).

To find out more about the CHANGE study, please contact **Beth Borosh** at **312-503-0482**.

MORE RESEARCH NEEDED ON MILD COGNITIVE IMPAIRMENT

If you have been diagnosed with mild cognitive impairment, please consider participating in a CNADC research program. The more people who enroll in research, the better the chance of identifying early cognitive changes and implementing interventions.

MCI occurs when a person experiences changes in one or more areas of cognitive functioning that do not interfere with the ability to carry out everyday activities. Although the changes are greater than those typical of the aging process, they do not cause the loss of daily function seen in a dementia like Alzheimer’s disease.

Scientists and clinicians are focused on early detection and prevention of MCI and dementia. Studying cognitive symptoms at an early MCI stage, when declines are subtle, is important for the development of research programs that can guide treatment and intervention. This research is still young, and little is known about what is helpful for this preclinical state. There have been a few clinical trials, but there is currently no FDA-approved drug treatment for MCI. Researchers are still trying to understand who is at risk for progressing from MCI to dementia and why some progress while some do not.

Those with MCI experience mild changes in thinking abilities related to learning new things. For example, they may forget recent

conversations or what they have read and may have difficulty paying attention, concentrating, thinking of words in conversation, and organizing and planning. Although the cognitive difficulties are noticeable to the person and others and are detectable on neuropsychological tests, they do not qualify for a diagnosis of dementia because they are not significant enough to interfere with such daily functions as paying bills, making important decisions, driving, cooking, and taking care of a household.

In some people these difficulties do not worsen over time, but a diagnosis of MCI puts a person at increased risk for developing Alzheimer’s disease, especially when the main problem is memory loss. When symptoms worsen to the point that they begin to interfere with the ability to carry out usual activities, they become characteristic of dementia.

If you have concerns about changes in your cognitive abilities or are wondering if the changes you are experiencing are related to the typical aging process, speak with your doctor about undergoing neuropsychological testing. If you have a diagnosis of MCI, please consider participating in a research study; call **312-926-1851** for information.

SURVEY PROBES SPEECH THERAPISTS' TREATMENT OF PPA

Primary progressive aphasia is a rare form of fronto-temporal degeneration caused by a disease process in which nerve cells degenerate in parts of the brain that control language. The degeneration affects such language elements as word finding, comprehension, naming, and use of grammar. In dealing with these symptoms, persons with PPA often turn to speech and language pathologists.

Anecdotal reports from people with PPA and their families suggest that many therapists make inappropriate recommendations and goals. Thus in October 2011 the CNADC teamed with the National Aphasia Association to email a nine-item survey to more than 1,200 SLPs.

Of the 135 SLPs who completed the survey:

- › 82 percent have heard of PPA
- › 76 percent have experience working with a person with PPA

Of those who have experience with a person with PPA:

- › 47 percent are very comfortable working with people who have PPA
- › 40 percent are somewhat comfortable working with people who have PPA
- › 13 percent are somewhat uncomfortable or uncomfortable working with people who have PPA
- › 96 percent provide family member and caregiver training and education on communication methods; of these:
 - » 65 percent recommend family education and training on communication strategies
 - » 34 percent recommend disease and aphasia education
 - » 20 percent recommend communication augmentation tool implementation

Of the SLPs who have experience with people living with PPA, 61 agreed to be on a national contact list that will be available to patients with PPA and families.

Interest in learning more about PPA was expressed by 112 respondents. The CNADC, the National Aphasia Association (www.aphasia.org), and the Association for Frontotemporal Degeneration (www.theaftd.org) are cooperating to provide SLPs with PPA educational content.

Although the survey showed that SLPs are practicing with the PPA population and helped identify their treatment methods, SLPs' level of experience, level of understanding, and treatment approaches remain somewhat unclear. Best-practice speech therapy treatment methods for people with PPA require more research.

Because of the uniqueness of the progressive aphasic changes experienced by a person with PPA, it is important that the person be linked to a speech and language pathologist trained in and experienced with this disease. Misunderstanding of speech therapy goals for people with PPA can have a great impact on the patient and the family's quality of life.

As with other forms of neurodegeneration, there are no medical cures and very few treatment options for PPA. However, non-pharmacological methods of intervention, including speech and language therapy, can help people with PPA and their families communicate successfully despite the progressive decline in language functioning.

Questions Asked of Speech and Language Pathologists

The survey sent to more than 1,200 speech and language pathologists asked the following nine questions:

- Have you ever heard of primary progressive aphasia (PPA)?
- Do you have experience as an SLP working with persons who have a diagnosis of PPA?
- How comfortable are you providing speech and language pathology services to a person with PPA?
- When working with patients with PPA, do you provide caregiver/family member training or education? If so, add a comment about what is involved in this training.
- When meeting patients with PPA, do you discuss the use of communication augmentation tools or devices? If so, please list some common tools or devices you recommend.
- When meeting patients with PPA, do you provide suggestions for environmental changes to improve communication? If so, please list some suggestions you provide.
- Would you like your professional contact information to be listed with other SLPs who have experience working with persons with PPA?
- Would you like to learn more about PPA?
- What are your credentials? How long have you been practicing as an SLP?

ATTENDANCE GROWING AT FTD AND PPA CONFERENCE



The CNADC's annual FTD and PPA Caregiver and Professional Education and Support Conference is one of the few opportunities for families and professionals to come together to learn about caring for someone with a diagnosis of frontotemporal degeneration or primary progressive aphasia.

The 2012 conference, held in March, brought together more than 350 family caregivers and professionals. The daylong event was held for the first time at the Northwestern University School of Law to accommodate the growing number of attendees.

CNADC director M.-Marsel Mesulam began the morning with an update on the state of FTD and PPA knowledge and research. Diana Kerwin, assistant professor of medicine at the Feinberg School of Medicine and clinician in the Neurobehavior and Memory Clinic, provided a comprehensive introduction to FTD and PPA. The conference keynote speaker, Geri Hall, clinical nurse specialist at Banner Alzheimer's Institute in Phoenix, discussed management of behaviors in FTD and PPA. The morning closed with a panel discussion that included Hall, Kerwin, and two family caregivers.

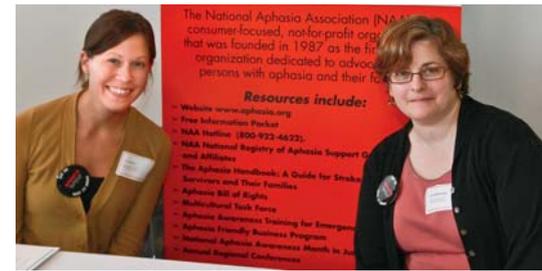
Lunch provided an opportunity for caregivers from all over the country to converse and to visit the resource and vendor fair.

Twelve afternoon breakout sessions, facilitated by CNADC staff and other local experts, focused on disease aspects, symptom management, and support. After the conference, attendees received a book that included handouts from each session.

Jennifer Medina, a neuropsychologist at the Neurobehavior and Memory Clinic and psychiatry and behavioral sciences instructor, closed the day with the reflective and moving session "Stress and Caregiving: Mindfulness as a Coping Tool." She ended by leading the audience in a meditation.

"Thank you for gathering such knowledgeable, helpful professionals and caregivers willing to share their coping methods and caring strategies with us," one attendee wrote. Another said, "Thank you to everyone involved. I always leave with more knowledge and insight and friends than I came in with."

For more information about the conference book or the next conference, which will be held November 4, 2013, please visit www.brain.northwestern.edu.



Top: Rosalind Hurwitz and Lisa Naylor represent the National Aphasia Association.

Middle: Participant Sheila Harding (right) receives information at the resource and vendor fair.

Bottom: Sara Siggelkow (left) and Marge Weber (center) speak with Mary Anne Reidner.



Left to right: Panelists Geri Hall, Diana Kerwin, Mark Toles, and Pati Bradstreet



Left: Diana Kerwin, plenary speaker and panelist

Right: Pati Bradstreet, panelist

CLINICAL TRIALS

DETECTION OF ALZHEIMER'S Before Significant Memory Loss

The **Feinberg School of Medicine** continues to enroll participants for the first national study to detect Alzheimer's disease in older people before they begin to have significant memory loss.

Researchers use imaging techniques and bio-marker measures in blood and cerebrospinal fluid that have been specially developed to track changes in the living brain. The goals are to identify who is at risk for Alzheimer's, track progression of the disease, and devise tests to measure the effectiveness of potential interventions.

The CNADC is one of several National Institute on Aging sites that are participating in the study, an expansion of the National Institutes of Health's Alzheimer's Disease Neuroimaging Initiative.

"This is an important study to develop ways for physicians to detect the disease before the person has overt memory loss," says Diana Kerwin, principal study investigator at the CNADC and assistant professor of medicine at Feinberg. "The earlier we can detect disease, the better chance there is to delay the memory loss or prevent it from happening at all. Early diagnosis is going to be key as far as making any further breakthroughs in the treatment of Alzheimer's disease and other memory disorders."

Potential participants include men and women ages 55 to 90 with early signs of memory loss that does not currently affect their daily lives. People already diagnosed with early-stage Alzheimer's disease can enroll in the study's Alzheimer's group.

"By taking part in the study," says Kerwin, "those who have Alzheimer's disease in their families or are concerned about their own memories would be contributing to our scientific understanding of the early markers of Alzheimer's disease pathology in the brain and also of normal aging."

To find out more about this study contact the coordinator, **Kristine Lipowski**, at **312-503-2486**.

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.

IVIG Studied for AD Patients

In collaboration with the CNADC, the Feinberg Department of Neurology is enrolling subjects in a new national clinical research trial examining the safety and effectiveness of intravenous immune globulin as a treatment for Alzheimer's disease.

According to a recent *New York Times* article (www.nytimes.com/2012/07/18/business/study-shows-drug-may-help-alzheimers-patients.html), early studies suggest that IVIG may help stabilize AD patients. However, a properly designed clinical trial is necessary to test effectiveness.

The study seeks to enroll men and women ages 50 to 89 with mild to moderate Alzheimer's disease who are already on stable doses of AD medications. Participants are randomly assigned to receive either IVIG or a placebo infusion every other week for 18 months. The first three infusions are given at the Northwestern Clinical Research Center and the rest at the subject's home. The participant must be able to undergo several standard magnetic resonance imaging scans and have a caregiver who can work with him or her throughout the study. There is no cost to participants for study-related exams, tests, and drug infusions. Participants and caregivers are compensated for their time.

The principal investigator for the Northwestern study ("A Phase 3 Randomized, Double-Blind, Placebo-Controlled Study of the Safety and Effectiveness of Immune Globulin Intravenous, 10 Percent Solution, for the Treatment of Mild to Moderate Alzheimer's Disease") is Darren Gitelman, associate professor of neurology and radiology at the Feinberg School. For more information please contact the study coordinator,

Sherrie Wolfe, at **312-503-2308**.

Two Studies: Behavioral-Variant Frontotemporal Dementia and Mild Cognitive Impairment

The **CNADC** will participate in a new therapeutic trial for people diagnosed with frontotemporal dementia. Potential participants include men and women under the age of 70 who have been diagnosed with behavioral-variant frontotemporal dementia (bvFTD). Enrollment will begin late this year or early 2013.

Another study will involve people diagnosed with mild cognitive impairment. This large-scale, multisite, exercise research study will begin in 2013. It is funded by the National Institutes of Health and the Alzheimer's Disease Cooperative Study.

To find out more about these research studies, contact the coordinator, **Kristine Lipowski**, at **312-503-2486**.

ALZHEIMER DAY ATTRACTS HUNDREDS

Harvard neurologist Reisa Sperling focused on the potential for and the barriers to Alzheimer's disease prevention as she delivered the Mendelson Lecture at CNADC's 18th annual Alzheimer Day in May. Associate professor of neurology at Harvard Medical School and director of the Center for Alzheimer Research and Treatment at Brigham and Women's Hospital, Sperling gave the lecture "Can We Detect AD a Decade before Dementia, and Why Would We Want To?"

More than 300 researchers, clinicians, family caregivers, and patients attended Alzheimer Day, which provided an update on the state of research and fostered communication among clinicians, scientific researchers, and the community living with AD. Many commented that they found the day informative and stimulating.

Attendees had the chance to speak with the more than 40 researchers who presented their work on Alzheimer's disease and related disorders (ADRD) at a poster session. Poster topics ranged from basic science research to nonmedical interventions for those living with a diagnosis. Tharinda Rajapaksha received the annual Carl and Marie Duncan Prize in memory research for his poster "The Alzheimer's Beta-Secretase Enzyme BACE1 Is Required for Accurate Olfactory Sensory Neuron Axon Guidance and Normal Glomerulus Formation in the Olfactory Bulb."

In a new feature of this year's event, the CNADC offered memory screenings, and more than 50 people participated.

The afternoon session focused on exploring creative arts interventions for people with dementia. Mary Mittelman, director of the psychosocial research and support program of the New York University Center of Excellence on Brain Aging, provided an introduction and overview of her research on NYU's chorus for people with ADRD and their caregivers. She also evaluated Meet Me at MOMA, the Museum of Modern Art's monthly program for people with dementia and their families. Mittelman's presentation was followed by clips from the documentary *I Remember Better When I Paint* and a short video about the Memory Ensemble, an improvisational acting program. The afternoon session ended with a panel of art, music, and dance therapists discussing the benefits of creative arts for those living with a diagnosis.

The 19th annual Alzheimer Day will be held May 9, 2013.



Social work intern Mary Popelar



External advisory board member Matt Frosch, MD, speaks with Duncan Prize winner Tharinda Rajapaksha (right).



Attendee Jeanee Hutchinson (center) speaks with sponsors.



Attendees had the opportunity to speak with sponsors throughout the day.



Mendelson Lecturer Reisa Sperling with CNADC director M.-Marsel Mesulam.



Left: Linda and Bob Mendelson (center) and family with Mendelson Lecturer Reisa Sperling (third from left), former CNADC board chair Craig Grannon (second from right), and CNADC director M.-Marsel Mesulam (right). Center: Mary Mittelman, the afternoon session's keynote speaker. Right: The CNADC's Mary O'Hara introduces a video about the Memory Ensemble.





Run4Papa Raises More than \$50,000 and Counting

Jason Boschan's journey to the Great Wall of China Marathon started

after he finished the 2010 New York City Marathon. When he and his brother Jared were leaving Central Park afterward, Jared mentioned the marathon that's considered the toughest anywhere: the race on the Great Wall of China. Jason didn't think he was up to the task, but he soon changed his mind—when his grandfather, Louis Heyman, a pediatrician for more than 50 years, was diagnosed with primary progressive aphasia, a rare form of dementia. Jason decided to run the Great Wall marathon in May 2012 to raise research funds to honor his grandfather and all people battling PPA.

After doing voluminous research on PPA, Jason Boschan contacted the CNADC in early 2011 to form a fundraising partnership. Based in Charlotte, North Carolina, he journeyed through nine states over the next 15 months, running more than 500 miles and raising \$54,000 for CNADC research—more than twice his initial target of \$20,000.

Boschan also set up a website, Run4Papa.com, and started networking through social media. His PPA video sparked interest locally, nationally, and internationally. The number of social media followers grew monthly, and they not only contributed money but also disseminated his videos, articles, and pictures to more than 50 countries. Sponsors lined up. Boschan hosted four fundraisers. He was not only having a tangible effect on families battling PPA but was also raising awareness among the vast numbers of people who had never heard of the disease.

Since simulating the Great Wall of China was impossible, Boschan trained for the run in a variety of settings: swimming pools, trail runs, mud races, half-marathons, the sunset cliffs in San Diego, stairs in high-altitude Denver, and the stairwell of the 100-story John Hancock Building in Chicago.

On race day at the Great Wall, Boschan—supported by more than 1,000 individual donors and 3,000 online followers—ascended and descended 5,164 steps over the 26.2 marathon miles.

The Run4Papa campaign is continuing; Boschan will announce phase 2 soon. To see photos from his journey so far, visit www.Run4Papa.com.

A MESSAGE FROM BOARD CHAIR TERRY CHAPMAN

Dear Friends,

The research and clinical services of the CNADC and the Neurobehavior and Memory Clinic depend on both public and private resources. While public funding supports the center's basic infrastructure, your donations help fund innovative research, patient care, caregiver support, and new therapies.

One of 30 National Institutes of Health Alzheimer's Disease Centers, CNADC helps lead an international effort to finding sensitive tools for discovering the earliest signs of memory impairment so that the diagnosis of Alzheimer's disease can be made as early as possible, at a time when treatments may be more effective. CNADC also is home to leading research programs on other forms of dementia, including primary progressive aphasia and frontotemporal degeneration.

The **Care Pathway Program** (page 3) is built on the philosophy that life enrichment programs for patients and families should be individualized to target specific strengths and weaknesses identified by quantitative neuropsychological investigations. Contributions fund the discovery of novel methods for matching individual patients to optimally suitable life-enrichment interventions.

The **SuperAging Project** (page 1) has recruited a group of elderly above the age of 80 with unusually preserved memory function. A new project in this area is to use a state-of-the-art imaging method to look for amyloid in the brains of these subjects. Findings would clarify not only the factors that allow successful aging but also whether amyloid should be the target of therapy in Alzheimer's disease.

If you have questions or would like to discuss giving options, please contact senior associate director of development **Barbara Monroe** at **312-503-0761** or barbaramonroe@northwestern.edu.

Sincerely,

Terry Chapman

Chair, CNADC Advisory Board

Hello!

WELCOME, NEW STAFF MEMBERS



Borna Bonakdarpour holds the Rosenstone Fellowship in cognitive and behavioral neurology. After receiving his MD from Tehran University of Medical

Sciences, he completed a research fellowship in aphasia and neurolinguistics at Northwestern. During his residency in neurology at the University of Arizona, he was also a research faculty member in the department of speech, language, and hearing sciences. Bonakdarpour specializes in the care of neurologic patients with cognitive impairments. His research interest is in neurobiology of language breakdown and recovery in poststroke aphasia and primary progressive aphasia.



Rakhee Ganti is research manager of Eileen Bigio's neuropathology laboratory. She was previously a geriatrics and gerontology research coordinator

at the Emory School of Medicine in Atlanta. Ganti completed a fellowship in molecular neuroscience at the Duke-NUS Graduate Medical School in Singapore and a BS in biological sciences at Georgia State University.



Adam Martersteck, a neuroimaging research coordinator, assists in the acquisition and analysis of MRI scans for the PPA study and coordinates Emily

Rogalski's PET imaging study. He received a BS in psychology from Indiana University.



Laura Martindale works with Sandra Weintraub and Mallory Ward as a research study assistant in the Clinical Core. She recently graduated from Princeton

University with a BA in ecology and evolutionary biology and a certificate in neuroscience.



Shoab Memon is a neuropsychiatry and behavioral neurology fellow. A graduate of Chicago Medical School, he completed a

psychiatry residency at the University of Chicago. Memon received undergraduate degrees in biology, history, and Spanish from the University of Illinois and Northeastern Illinois University. His interests include neuropsychiatric symptoms of traumatic brain injury.



Melanie Peterson is a research technologist splitting her time between the cognitive and molecular morphometry and the neuropathology

laboratories. She earned bachelor's degrees in both chemistry and biology at the University of Pittsburgh, where she also participated in the translational neuroscience program and the human brain tissue donation program. Most recently she was a research specialist at the University of Chicago.



Amanda Rezutek is a research assistant within the PPA and SuperAging programs. She received a BA in psychology from the University of Minnesota, where her

honors thesis focused on personality correlates of specific substance use and abuse. Rezutek hopes to learn more about helping families with PPA and other dementia-related impairments.



Kristen Whitney is a research assistant for the PPA research program and the SuperAging study. She received a BS in cognitive neuroscience

from the University of California, San Diego. Previously she was a research assistant in a neuropathology lab at UCSD Medical School and worked at the Alzheimer's Association.

Thank You, Departing Staff

The CNADC expresses gratitude and deepest appreciation to staff who have left in the past year: **Alejandra Balen, Joseph Boyle, Joseph Cooper, Nancy Kennedy, and Hyung-Sub Shim.** Thank you for your work and dedication to the Neurobehavior and Memory Clinic, CNADC research, and the patients and families we serve. We wish you the best in your next endeavors.

PPA Research Studies Funded

The two studies making up the PPA research program have been awarded five-year grants.

Funding for the “Language in Primary Progressive Aphasia” study led by CNADC director **M.-Marsel Mesulam** has been renewed for five years by the National Institute on Deafness and Other Communication Disorders. The study uses MRI, neuropsychological testing, and other neurophysiological measures to extensively classify PPA. One of the largest PPA studies to date, it has enrolled 85 participants diagnosed with PPA and has generated more than 30 journal articles in its first five years.

Emily Rogalski, research assistant professor at the CNADC, was awarded a five-year grant from the National Institute of Neurological Disorders and Stroke for a longitudinal brain-imaging study examining factors that influence disease progression, symptom severity, and their relationship to underlying pathology in PPA. Participants in her “MRI, Anatomy, and Progression in PPA” study will undergo structural MRI scans and neuropsychological testing every 6 months during an 18-month period. Each subject will also have an amyloid PET scan to determine whether he or she has Alzheimer pathology, which can have implications for future therapeutic plans. Data from the study will also provide quantitative benchmarks for clinical trials and disease-staging expectations for patients and families.

Once a participant is enrolled, the PPA research program provides transportation, accommodations, and meal reimbursement for the participant and one companion. Those interested in participating may contact **Christina Wieneke** at **312-908-9681** or **c-wieneke@northwestern.edu**.

Another SuperAging Study Funded

Tamar Gefen, a clinical neuropsychology PhD candidate, has received a grant from the Northwestern University Clinical and Translational Sciences Institute for her translational investigation of factors that differentiate supernormal from normal aging. Gefen hypothesizes that superagers are likely immune to Alzheimer’s pathology, primarily in the cingulate gyrus, a key brain region responsible for attention, motivation, and memory. Gefen collects neuropsychological and neuroimaging data from superagers and offers them the opportunity to participate in a brain donation program. Revealing the neurobiologic substrates of superaging can provide strategies for helping the “normal” elderly maintain cognitive function, and it may aid in the understanding and treatment of certain dementias, says Gefen.



Sandra Weintraub with Ole-Petter Ottersen, dean of the University of Oslo, in front of murals by Norwegian painter Edvard Munch

Weintraub Leads Neuropsychological Society

Sandra Weintraub, director of the CNADC Clinical Core, is this year’s president of the International Neuropsychological Society, a group of nearly 5,000 members who conduct research on brain-behavior relationships in health and disease. Many also work in academic medical centers, where they evaluate people with neurobehavioral disorders.

Weintraub gave a presidential address in June at the society’s midyear meeting in Oslo, Norway. Her talk, “Neuropsychological, Neuroanatomical, and Neuropathologic Phenotypes of Dementia,” outlined a system for classifying clinical dementia syndromes. The system differentiates among the different levels of dementia characteristics, from the cognitive and behavioral symptoms expressed by patients in clinicians’ offices to the patterns of brain dysfunction observed on structural and functional neuroimaging to the underlying neurodegenerative pathology that actually causes the dementia.

With 870 attendees, this was the society’s largest-ever midyear meeting. Its midyear meetings are always held outside North America.



DEPRESSION OFTEN ACCOMPANIES COGNITIVE DISEASE

Among people with Alzheimer's disease, 20 to 25 percent experience depression, which is also a frequent neuropsychiatric complication

in those diagnosed with related disorders such as mild cognitive impairment, Lewy body dementia, and vascular cognitive impairment. Depression also affects people diagnosed with primary progressive aphasia; studies have shown that one in three people diagnosed with PPA experience significant symptoms of depressed mood.

Particularly in the early stages after a cognitive diagnosis, depression may stem from a heightened awareness of new difficulties and a decrease in social interaction. For instance, when a person with PPA (a rare form of dementia in which the ability to use and understand language is progressively lost) can no longer answer the telephone, experiences problems in conversation, or has to retire from work prematurely, social contacts diminish, self-confidence and identity suffer, and everyday life is turned upside down.

Besides emotional factors, depression may be due to an underlying biological cause related to the disease and may be a sign that cognitive impairment is progressing. Whatever the cause, depression exacerbates impairment in functioning, lessens quality of life, intensifies caregiver distress, and can lead to earlier institutionalization. It is important to understand that early assessment and treatment of depressive symptoms is important and can improve quality of life.

Individual counseling by a licensed clinician such as a psychologist or a clinical social worker can help the person with cognitive impairment develop helpful strategies and attitudes to cope with losses and identify ways to compensate.

Support groups offer an opportunity to explore relevant issues or concerns with peers in a structured environment.

Creative arts therapies, including music, dance, and art therapy, have been shown to promote relaxation, support concentration, enhance self-esteem, and offer purpose for persons with cognitive impairment.

Meaningful activity includes activities that offer feelings of success, joy, and purpose. Daily meaningful activities can help prevent and combat depression. When people with cognitive difficulties experience trouble participating in hobbies or familiar activities, it is important to replace this loss with something engaging and meaningful. Success may be found in activities that the person has never done before or in familiar activities that can be modified.

Rehabilitation services include speech therapy, occupational therapy, and physical therapy. Some of these services may be available at a local rehabilitation center or set up in the person's home. These services teach patients and family members techniques to maximize communication and independence, despite the changes caused by the condition, and can help improve mood by increasing confidence and self-worth.

Medical treatments for depression include antidepressant and/or anti-anxiety medication. Typically, these medications have tolerable side effects and are effective. Monitoring the person taking the medication is important in ensuring its effectiveness and in determining any necessary adjustments. Primary-care physicians, psychiatrists, and other physicians can assist families exploring medication options.

The Neurobehavior and Memory Clinic provides these services. Please call **312-695-9627**.

New CNADC Professorship for Mesulam

CNADC director **M.-Marsel Mesulam** is the inaugural holder of the CNADC's new Ruth Dunbar Davee Professorship of Neuroscience. He had held the Dunbar Chair in Psychiatry and Behavioral Sciences at the Feinberg School for 18 years. The Ruth Dunbar Davee Professorship is Northwestern's first named professorship to focus on Alzheimer's disease and related fields. It combines the legacy of Ruth Dunbar Davee, who made a major gift that led to the CNADC's creation in 1994, and the vision of the Davee Foundation.

Clinical Core Responsible for Facilitating Research

The Clinical Core is one of the five cores of the Northwestern Alzheimer's Disease Core Center, one of the CNADC's two main enterprises. Headed by Sandra Weintraub, professor of psychology, the Clinical Core is responsible for recruiting research participants and facilitating researchers' access to the participant registry.

Over the 16-year lifetime of the CNADC, the Clinical Core has enrolled more than 1,700 people in its studies. Nearly 500 are now being followed annually. In the past two years the core has supported 22 research studies and has helped scientists obtain funding for eight federal grants and nine grants from non-federal agencies. In addition, Clinical Core participants have been studied in six clinical trials, and investigators have published 35 papers and 20 abstracts over the past two years.

The resources of the Clinical Core enable research on Alzheimer's disease within the institution and with collaborators across the United States and abroad. When a researcher wants to study a question—for example, the relationship between sleep and memory in older people with early Alzheimer's disease—the Clinical Core identifies suitable participants for referral. The potential participants have already been evaluated and classified (cognitively normal, mild cognitive impairment, or early Alzheimer's disease). Research participants are characterized in terms of their medical histories, family histories, and medications. They are also administered a series of research tests of cognitive functions and undergo a research neurological examination. They are followed annually. Each is asked to provide a study partner—a family member or close friend who can observe any symptoms of possible cognitive or functional decline.

Each Alzheimer's disease center differs in the emphasis of its research community. Northwestern specializes in the so-called atypical dementias of primary progressive aphasia and behavioral-variant frontotemporal dementia. In addition, Northwestern

researchers are exploring the full spectrum of cognitive aging. One study involving superagers—people over age 80 who are maintaining memory and other cognitive abilities at the level of younger people—aims to understand this phenomenon and to learn whether Alzheimer's disease can be avoided (see story on page 1). A new study involves people with mild cognitive impairment, a condition that may signal the beginning of Alzheimer's disease (see page 4).

Among recent Northwestern research highlights was a study by Tamar Gefen, a neuropsychology student, and her CNADC colleagues (*Brain*, 2012). Gefen studied patients with the clinical syndrome of primary progressive aphasia whose postmortem examinations showed Alzheimer pathology. She showed that the neurofibrillary protein abnormalities associated with the PPA diagnosis were concentrated in the parts of the brain that normally control ability to use language. This was the first time that Northwestern

researchers were able to confirm a correspondence between the location of the pathology in the language areas of the brain and the salient dementia symptom of aphasia.

Another research highlight was a collaborative study (*Journal of the International Neuropsychological Society*, 2012) carried out by C. E. Westerberg (psychology) with colleagues in psychology (Ken Paller) and neurology (Phyllis Zee) and the CNADC. They demonstrated that in people with the amnesic form of mild cognitive impairment, there is a correlation between sleep stages and the next day's memory recall after learning new information. Amnesic MCI is diagnosed when a person has abnormal scores on tests of short-term recall but normal scores on tests of other thinking abilities and has no problems in routine daily functioning. The results of this study imply that sleep contributes to the consolidation of what one learns from one day to the next and that changes in sleep patterns can contribute to memory loss in MCI.

Other Cores of the Alzheimer's Center

In addition to the Clinical Core, the Northwestern Alzheimer's Disease Core Center—one of 30 such centers funded by the National Institute on Aging—has four other cores.

The **Administrative Core** consists of the center director, M.-Marsel Mesulam, and administrative staff, who maintain cohesiveness among the center's sectors and set center priorities.

The **Neuropathology Core**, led by Eileen Bigio, maintains the center's brain bank. Brain donations are obtained from people who were followed in the Clinical Core during their lifetimes and who committed to brain autopsies. A definitive diagnosis of the dementia-causing disease can be made from an autopsy. After the autopsy the tissue is banked and distributed to approved research collaborators investigating molecular aspects of dementia-causing diseases and of healthy cognitive aging.

The **Biostatistics and Data Management Core**, led by Alfred Rademaker, maintains the center's database, assists researchers in experimental design and data analysis, and submits data to the National Alzheimer Coordinating Center.

The **Education Core**, directed by Darby Morhardt, is responsible for educating the community and Northwestern scientists (investigators, students, and fellows) about Alzheimer's disease and related disorders. It also helps recruit participants to Clinical Core research and creates quality-of-life programs for people with dementia and their caregivers.

CORE AND AFFILIATED FACULTY

Name	Rank	Department	Research Area(s)
Vania Apkarian, PhD	Professor	Physiology	Resting networks
Susan Benloucif, PhD	Adjunct associate professor	Neurology	Sleep and memory in older adults
Eileen Bigio, MD	Professor	Pathology	FTLD, TDP-43, PPA
Lester Binder, PhD	Professor	Cell and Molecular Biology	Tau, axonal transport
Borna Bonakdarpour, MD	Instructor	Neurology	Behavioral neurology
Beth Borosh, PhD	Assistant professor	Psychiatry	Neuropsychology
Hans Breiter, MD	Professor	Psychiatry	Cognitive neuroscience
John Csernansky, MD	Professor	Psychiatry	MRI as MCI biomarker
John Disterhoft, PhD	Professor	Physiology	Memory and age
Honxing Dong, PhD	Assistant professor	Psychiatry	Stress in AD mice model
Adriana Ferreria, MD, PhD	Associate professor	Cell and Molecular Biology	A β -Tau interactions
Changiz Geula, PhD	Professor	CNADC	Cholinergics and glia in AD
Darren Gitelman, MD	Associate professor	Neurology	DTI in PD
Jay Gottfried, MD, PhD	Associate professor	Neurology	fMRI in AD, PPA
Robert Hanlon, PhD	Associate professor	Psychiatry	Neuropsychology
Scott Heller, MD	Associate professor	Neurology	Dementia in ALS
Diana Kerwin, MD	Assistant professor	Medicine	Gerontology, obesity in AD
William Klein, PhD	Professor	Neurobiology and Physiology	A β oligomers, insulin
Pascale Lacore, PhD	Assistant professor	Neurobiology and Physiology	A β oligomers
Jennifer Medina, PhD	Instructor	Psychiatry	Neuropsychology
Shoaib Memon, MD	Instructor	Psychiatry	Neuropsychiatry
M.-Marsel Mesulam, MD	Professor	Neurology	Networks in AD, PPA
Darby Morhardt, MSW	Associate professor	CNADC	Education, quality-of-life programs
Toshio Narahashi, PhD	Professor	Pharmacology	Memory enhancement
Hande Ozdinler, PhD	Assistant professor	Neurology	Gene networks in selective vulnerability
Ken Paller, PhD	Professor	Psychology	ERP and memory in MCI
Todd Parrish, PhD	Associate professor	Radiology	fMRI physics of PPA, AD
Peter Penzes, PhD	Associate professor	Physiology	A β toxicity on dendrites
Alfred Rademaker, PhD	Professor	Preventive Medicine	Biostatistics
Paul Reber, PhD	Professor	Psychology	Cognitive rehabilitation in MCI
Deborah Reed, MD	Assistant professor	Psychiatry	Neuropsychiatry
Sarah Rice, PhD	Assistant professor	Cell and Molecular Biology	Tau and kinesin
Emily Rogalski, PhD	Assistant professor	CNADC	Cognitive neuroimaging of aging and dementia
Aryeh Routtenberg, PhD	Professor	Psychology	Axon sprouting and plasticity in AD
Teepu Siddique, MD	Professor	Neurology	ALS/FTLD
Tanya Simuni, MD	Associate professor	Neurology	Neurology of PD
James Surmeier, PhD	Professor	Physiology	Parkinson's physiology
Cynthia Thompson, PhD	Professor	Communication Sciences and Disorders	Neurolinguistics in PPA
Fred Turek, PhD	Professor	Neurobiology and Physiology	Sleep and age
Robert Vassar, PhD	Professor	Cell and Molecular Biology	BACE, transgenic mice
Lei Wang, PhD	Assistant professor	Psychiatry	Hippocampus MRI in AD
Sandra Weintraub, PhD	Professor	Psychiatry	Neuropsychology, UDS
Craig Weiss, PhD	Associate professor	Cell and Molecular Biology	Memory in A β mice
Catherine Woolley, PhD	Professor	Neurobiology and Physiology	Estrogen and plasticity
Jane Wu, PhD	Professor	Neurology	TDP-43, PGRN in fly
Alice Wyrwicz, PhD	Adjunct associate professor	Biomedical Engineering	Ex vivo NFT imaging
Phyllis Zee, MD, PhD	Professor	Neurology	Sleep and memory in MCI

La Memoria Project Improves Latino Access to Dementia Resources

Minorities profit from better understanding of dementia risk factors and better prevention and treatment when they are included in dementia research. Effective recruitment and retention of minorities in research, however, requires community partnerships. Through one such partnership the CNADC and the Erie Family Health Center in Chicago have improved the evaluation, treatment, and care options for cognitively impaired Spanish-speaking patients.

The CNADC began partnering on La Memoria Project with the federally qualified Erie Center in fall 2010, thanks to pilot funding from Northwestern Memorial Hospital's Physician Community Engagement Grants. Collaborating on the project were the Erie Center's David Buchanan, MD, and Sheila Fleming, MSW, and the CNADC's Diana Kerwin, MD, and Darby Morhardt, MSW. Their objectives were to provide early detection and treatment of Alzheimer's disease and to improve access to dementia care and resources for the largely Latino community that EFHC serves.

During the pilot stage a bilingual social work intern provided cognitive screenings for people in the target group, helped manage clinical collaboration between CNADC and EFHC, and facilitated access to dementia care services. Data were gathered on the feasibility of identifying, screening, and referring the population for further diagnostic evaluation and services. La Memoria completed 25 psychosocial assessments and 26 cognitive evaluations (labs and brain imaging). Two patients were referred for full neuropsychological testing. The project model and results were disseminated in poster sessions at the 2011 Alzheimer's Research Coordination Center meeting and the 17th annual Northwestern Alzheimer Day in 2011.

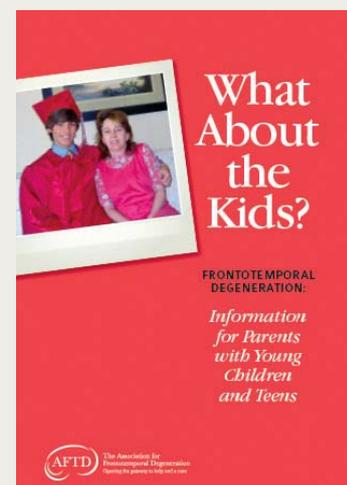
Last spring Lina Ariza, a visiting doctor from Colombia, followed up with patients and families to monitor how patients were progressing and how helpful they had found the recommendations. Ariza also gave a talk on brain health to a group of more than 65 Spanish-speaking seniors at the West Town/Logan Square Senior Center, a few blocks from EFHC. Several attendees expressed interest in receiving more information on memory screening and research participation.

Guide Helps Children of FTD Patients

The national Task Force on Families with Children,

convened in 2010 by the Association for Frontotemporal Degeneration, has produced a guide for parents to help children of FTD patients. *What about the Kids?*, a sensitive, practical guide, can be downloaded from AFTD's website, www.theaftd.org, along with the task force's report.

Darby Morhardt, CNADC's education core director and clinical social worker, is a member of the task force. Its goals are to articulate the specific issues of parents and their children and teens; identify existing resources; prioritize projects for AFTD to implement for these families; and stimulate the attention of a wider range of healthcare and social service providers to their needs. The group uses a broad, descriptive approach to gather data from currently affected parents and their children, young adults reflecting on their earlier years at home with an affected parent, and professionals who work with hundreds of affected families. The task force's work raises hopes for the development of additional resources for children and teens.



COGNITIVE NEUROLOGY AND ALZHEIMER'S DISEASE CENTER

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CNADC LAUNCHES UPDATED WEBSITE

A revised CNADC website, launched in July, updates content and graphics and streamlines access to important information. CNADC collaborated with the Feinberg School of Medicine Office of Communications on the update, which involved several CNADC staff members. The goal was to make www.brain.northwestern.edu more visually appealing while maintaining the information visitors expect.

The site will change often and keep information about support groups, education events, research studies, and research grants up to date. It is an important tool in matching clients with the many services the CNADC offers.

"Many times our website serves as the first point of contact for our many different types of clients," says Kevin Connolly, CNADC business administrator. "Whether a recently diagnosed person is looking to join a research study, or a family member is looking to join a support group, our goal is to make information easy to find." The new website also has plenty of information for researchers, including grant opportunities, Alzheimer's disease seminars, and forms to request tissue or subjects for research studies.

The website receives over 80,000 visits a year and has many resources for patients, caregivers, researchers, and students. The most popular pages on the website are related to information about disorders such as Alzheimer's disease and primary progressive aphasia. The CNADC site has one of the top rankings for searches about primary progressive aphasia.

UPCOMING EVENTS

Alzheimer's Disease Seminar Series

Monthly during the 2012-13 academic year.

See www.brain.northwestern.edu/about/events/adseminars.html.

19th Annual Alzheimer Day

Thursday, May 9, 2013, 11:30 a.m.-4 p.m.

FTD/PPA Caregiver Education and Support Conference

Monday, November 4, 2013

For information about all events, contact **Darby Morhardt** at **312-908-9432** or **d-morhardt@northwestern.edu**.