

CNADC NEWS

Produced by the COGNITIVE NEUROLOGY

AND ALZHEIMER'S DISEASE CENTER

RECORD ATTENDANCE AT FTD/PPA CAREGIVER CONFERENCE



This year's Frontotemporal Dementia/Primary Progressive Aphasia Caregiver Education and Support Conference, held at the Feinberg School of Medicine in March, had the largest attendance in the event's history, attracting more than 300 people from the United States, Canada, and Ireland. The annual conference is designed for family caregivers of persons with FTD and PPA.

Attendees were updated on current research and CNADC services. The morning sessions included well-received presentations by Bradley F. Boeve, professor of neurology at the Mayo Clinic in Rochester, Minnesota, and Deborah Reed, assistant professor of psychiatry and behavioral sciences at the Feinberg School and neuropsychiatrist with Northwestern's Neurobehavior and Memory Clinic.

Boeve, Reed, and three caregiving family members participated in a panel discussion to end the morning sessions.

In the afternoon several breakout sessions were offered for families—including Managing Behaviors, Families with Children and Teens, Communication Challenges in PPA, and Genetics and FTD/PPA—and a support group was offered for persons with PPA.

One participant's feedback—"I have a much better understanding of the disease and what's ahead. We are not alone in this!"—typified the positive response many expressed and their gratitude for valuable information and the opportunity to meet others.

This year's conference was supported in part by the Association for Frontotemporal Degeneration and the National Aphasia Association.

The conference booklet can be downloaded at www.brain.northwestern.edu/events/ftdppa.html. To purchase a hard copy, please e-mail CNADC-Admin@northwestern.edu. Also available for purchase from the CNADC is a 20-page booklet titled *Reflections: Reflecting on Life with FTD and PPA*, a compilation of essays, poems, photos, and paintings from patients and caregivers.



If you are interested in more information or would like to schedule a consultation, contact

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M.-Marsel Mesulam

Dear Friends and Colleagues:

Welcome to the 2011 *CNADC News*. A year is a very long time in the life of the CNADC. This newsletter covers only some of our notable developments. I hope you will find the contents interesting and will feel free to contact me if you have comments or questions.

Once every five years, Alzheimer's disease centers in the United States undergo an ordeal known as a competitive renewal application. We are required to prepare a document, hundreds of pages long, containing details of our achievements and our plans. The document is rated by experts to determine which centers are funded by the National Institutes of Health for another five years.

The CNADC just went through this process. I am immensely proud that we received the highest score in the entire group of applicants—in fact, the highest possible score. The credit belongs to the entire staff and faculty of the CNADC. Special thanks and congratulations go to the members of the executive committee: John Disterhoft, associate director; Sandra Weintraub, Clinical Core leader; Nancy Johnson and Alfred Rademaker, Data Core leaders; Eileen Bigio, Neuropathology Core leader; Darby Morhardt, Education Core leader; and Kevin Connolly, center administrator.

While we are delighted at the outcome, there are huge challenges that remain as we look for new ways to treat and prevent Alzheimer's disease, primary progressive aphasia, frontotemporal degenerations, and related disorders.

This past year witnessed the passing of a great friend of the CNADC, Ruth Dunbar Davee (see page 15). Ruth and her sister Evelyn endowed the professorial chair that I proudly hold. Ruth and her husband, Ken Davee, also provided the principal gift that allowed the establishment of the CNADC at the medical school. A woman of great achievement, compassion, and vision, Ruth lived 99 extraordinarily full years and enriched the lives of many others. Her legacy will be kept alive through the work of the CNADC.

I want to thank the CNADC Community Advisory Board for its wise counsel and generous support. Craig Grannon, who took the helm at the completion of Donna Elrod's highly effective term, has already initiated a number of public relations and fundraising innovations. The CNADC is grateful to Craig, Donna, and all other members of the board for their dedication to the goals of excellence in patient care and research at Northwestern University.

I also thank the diagnosed individuals and the families who have assisted the CNADC's advocacy and community education efforts. Your stories and your voices have contributed to greater community awareness about Alzheimer's disease and related disorders and have played a part in influencing public policy. Thank you for courageously sharing your experiences, your struggles, and your hopes with us and with others. Your dedication to this cause is greatly appreciated.

With warm regards,

M.-Marsel Mesulam, MD

CNADC Director and Ruth and Evelyn Dunbar Professor of Neurology, Psychiatry, and Psychology

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

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EDUCATION AND OUTREACH

RESOURCE NAVIGATOR BASES RECOMMENDATIONS ON SYMPTOMS

The CNADC’s new Resource Navigator offers patients and their families a nonpharmacological intervention tailored to a patient’s symptoms.

Following a diagnostic evaluation at the CNADC’s Neurobehavior and Memory Clinic, careful attention is given to the patient’s diagnosis and, perhaps more important, the patient’s symptoms. Our Resource Navigator recommends interventions to address particular symptoms affecting the patient’s quality of life and offers educational material about the diagnosis and the affected cognitive domain or pathway.

Pathways are usually one or more of the following: language decline (e.g., difficulty with word finding, naming, fluency); behavioral disturbances (e.g., agitation, disinhibition, repetitive activities); visuospatial disturbances (e.g., analyzing and understanding the world around you); and memory loss (e.g., remembering what happened a short time ago).

Attention is also given to the patient’s remaining abilities and strengths. Evidence indicates that attention to these can help to preserve cognitive functioning. Recommendations—including special exercise routines, nutritional programs, and stimulating activities—are made to support a cognitively healthy lifestyle.

Right now, the progression of dementia cannot be stopped, but the Resource Navigator can temporarily combat the symptoms and help the patient and family maintain the highest possible quality of life. Please contact the Neurobehavior and Memory Clinic at 312-695-9627 to learn more about the Resource Navigator.

CARE PATHWAY	REFERRAL	RECOMMENDATIONS
Language	Speech and language pathologist	Language assistive devices
Behavioral	Education and counseling	Safety products to prevent wandering Tips and strategies for family caregivers
Visuospatial	Occupational therapist	Tips about effects of visual changes and possible aids
Memory	Cognitive rehabilitation therapist	Memory assistive devices and strategies

Common referrals and recommendations based on care pathway.

Younger Onset Support Group Formed

Findings from the CNADC’s Younger Onset Program have resulted in the creation of a Younger Onset Support Group for both patients who are in the earlier stages of cognitive change and their family members.

The Younger Onset Program held three focus groups to explore the unique needs of people diagnosed with dementia at an unusually young age and of their families.

Although age may increase the risk of developing Alzheimer’s disease, dementia has been diagnosed in an estimated 200,000 people in the United States under age 65. This younger-onset population faces uniquely challenging circumstances. Most services for cognitively impaired adults, such as adult day programming and residential facilities, are designed for frail older adults and are not equipped for a younger person’s needs.

The last focus group in November 2010 was attended by 23 people—9 patients in the early stages of AD and related dementias and 14 family members. Participants ranged in age from 25 to 62. They said that they have a strong desire to just be with others living with the same challenges, in the same generation, with similar interests and life paths. They also want access to meaningful activities (volunteering, exercise programs, cultural activities) that are age appropriate and take into account a person’s cognitive changes. They also expressed a need for educational classes, materials, and services to assist with financial planning; to access age-appropriate community services; and to address family issues, particularly those of children and teens, and other relevant topics.

The Younger Onset Program is funded by donations from the friends and family of Rae and John Hernandez. John was diagnosed with younger-onset Alzheimer’s at age 45 and was followed by clinicians at the CNADC throughout the course of his illness. When he died, his widow, Rae, asked that donations be given to the CNADC in lieu of flowers.

The program resulting from the focus groups’ identification of needs is the first of what is hoped to be many more programs specific to the needs of people under 65 diagnosed with dementia. For more information about the support group, please contact **Jaimie Robinson** at **312-695-0450** or **jaimie-robinson@northwestern.edu**.

EDUCATION AND OUTREACH

Mindfulness Therapy for Patients and Caregivers Tested

Coping with Alzheimer's disease brings a heavy emotional load to patients and their caregivers, and the CNADC is examining new ways to help. Beginning in 2010 and continuing this year, a group of scientists and clinicians is testing an innovative program of weekly therapy sessions for small groups of volunteers.

Mindfulness therapy is increasingly prominent as a method for helping people with many different problems and challenges. In mindfulness therapy, the therapist works to help people learn a set of attentional and emotional skills that can lessen the weight of an uncertain future and enhance the ability to enjoy the present moment.

Clinicians at the University of Massachusetts made some of the early strides in designing these therapeutic methods. Training begins with exercises to enhance one's ability to fully attend to the experiences of the present moment, extending these skills to many of the challenges we all face with emotional tugs in many directions that can take us away from our inherent stability.

These methods are now being made

available in Chicago to small groups through the CNADC, thanks to grant support anticipated from the Illinois Department of Public Health.

As is well known, patients with Alzheimer's disease and their caregivers face increasing stress from the progressive nature of the disease. Caregivers are often prone to depression and other health disorders as a result. Past research on mindfulness therapy in other disorders has shown benefits that included reduced physical pain, decreases in perceived stress and depression, and improved immune function.

Participants in CNADC's program gather weekly with Michael Maslar, director of Northwestern's Mindfulness and Behavior Therapies at the Family Institute. Sessions are designed to be accessible to people in early stages of memory loss. As part of the program, all participants are expected to practice the skills taught by Maslar in daily homework activities that he assigns.

The program also includes assessments of cognitive abilities and emotional well-being before and after the intervention.

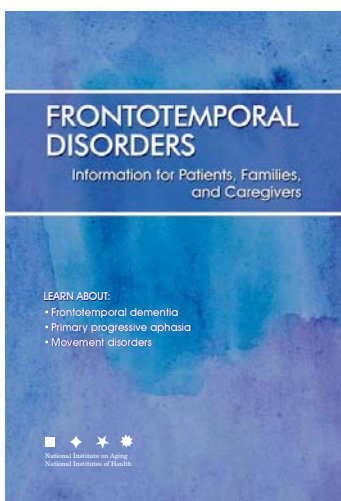


Tests are administered as part of a research endeavor designed to evaluate the potential usefulness of the intervention. Preliminary findings are promising; many participants to date have indicated that they felt an improved ability to handle stressful situations. Data collection continues.

The most recent session began in April. Additional sessions may be scheduled, depending on finding new research funding from outside sources. Anyone interested in learning more and possibly participating is encouraged to contact **Jessica Creery** at **847-491-7725** or **j-creery@northwestern.edu**.

Ken Paller, a CNADC affiliate faculty member and professor in Northwestern's psychology department, leads the research assessments of the mindfulness therapy program.

FTD BOOKLET WRITTEN BY CNADC FACULTY AND COLLABORATORS



The CNADC's Sandra Weintraub, professor of psychiatry and behavioral sciences, and Darby Morhardt, social worker and research associate professor, were collaborators on an educational booklet for persons with frontotemporal dementia and their families.

Weintraub and Morhardt collaborated on *Frontotemporal Disorders: Information for Patients, Families, and Caregivers* with gerontological nurse Jennifer Merrilees, an associate clinical professor at the University of California, San Francisco, and Catherine Pace-Savitsky and Susan Dickinson of the

Association for Frontotemporal Dementias. Published by the National Institute on Aging's Alzheimer's Disease Education and Referral Center in fall 2010, the booklet serves to fill an information gap by describing what is known about the different types of FTD disorders, ways they are diagnosed, and strategies and resources for communicating and coping.

The booklet can be downloaded without cost at **www.nia.nih.gov/Alzheimers/Publications/FTLD** or obtained by calling the Alzheimer's Disease Education and Referral Center at **800-438-4380**.

EDUCATION AND OUTREACH

Early-Stage Patients

Benefit from Improvisation

Requiring no scripts, no memorization, and no previous experience, an improvisational theater program called the Memory Ensemble is responding to previously unmet creative needs of people with early-stage memory loss.

The Memory Ensemble was conceived in late 2009 by social work staff from the CNADC and a teaching artist from Lookingglass Theatre Company in Chicago to provide challenging and supportive creative learning opportunities for persons with early-stage Alzheimer's disease and related conditions. Fourteen people have participated so far.

The program offers improvisational acting classes in an emotionally supportive and cognitively stimulating environment. In the sessions Memory Ensemble members learn to use their instincts, creativity, and spontaneity as they improvise together.

Results of a 2010 pilot study showed that the program improved participants' quality of life and feelings of empowerment. Participant outcomes will continue to be studied in another Memory Ensemble program planned for this fall.

The goal is to produce a curriculum manual so that the Memory Ensemble program can be replicated in other communities.

For more information contact **Mary O'Hara** at **312-503-0604** or **m-ohara@northwestern.edu**.

Alzheimer's and Related Illnesses

Spousal Support Group

Fourth Monday of the month, 10:30 a.m.–noon
645 North Michigan Avenue (entrance on Erie), suite 630,
Department of Medicine conference room

Adult Children Caregiver Support Group

First Monday of the month, 6–7:30 p.m.
251 East Huron Street, Feinberg Pavilion, third floor, room B

Frontotemporal Dementia (FTD) and Primary Progressive Aphasia (PPA) Caregiver Support Group

Third Monday of the month, 6–7:30 p.m.
251 East Huron Street, Feinberg Pavilion, third floor, room C

Early-Stage Memory Loss Education and Support Group for Persons with Alzheimer's or a Related Dementia and Their Families

Spring and fall sessions (12 weeks each)
Feinberg School of Medicine

Early-Stage PPA Patient Education and Support Group

Ongoing. Interview required for participation.
Feinberg School of Medicine

Younger-Onset Support and Education Group

Ongoing. Interview required for participation.
Feinberg School of Medicine

For more information about any of these support groups, contact **m-ohara@northwestern.edu** or **312-503-0604**.

Early-Stage PPA Support Group Expands

The Early-Stage Education and Support Group for Individuals with PPA has expanded to a twice-monthly, 10-session program after a successful 5-session pilot program in 2010.

The group educates and provides support to persons diagnosed with early-stage primary progressive aphasia and related disorders and their family members. One monthly session is for diagnosed persons only, and the other includes their family members as well. For more information contact **Christina Wieneke** at **c-wieneke@northwestern.edu** or **312-908-9681**.

RESEARCH

SUPERAGING STUDY

FOCUSES ON STILL-SHARP MEMORIES

Rather than studying the brain by focusing on what goes wrong, the CNADC's SuperAging Study takes the unique approach of looking for factors that may contribute to optimal cognitive aging.

The study enrolls people over the age of 80 who have exceptional memory abilities. Researchers are examining neuropsychologic, neuroanatomic, neuropathic, demographic, genetic, and pathologic features.

Preliminary results of the ongoing study, reported at the International Neuropsychological Society meeting in Boston in February, demonstrate that superagers' personalities tend to resemble 50-year-olds rather than their peers.

The SuperAging Study was also featured in a Chicago Public Radio program called *Clever Apes*. Researchers



Changiz Geula, M.-Marsel Mesulam, and Emily Rogalski and one of the participants in the SuperAging Study were interviewed. The interviews and the associated blog can be found at www.wbez.org/gspitzer/2010/09/clever-apes-this-nonagenarian-did-more-than-you-did-today/37936#more-37936.

The SuperAging Program is supported by the Ken and Ruth Davee Neurobiology Research Initiative Fund.

Participants Needed for Early Memory Loss Study

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

Researchers will use imaging techniques and biomarker measures in blood and cerebrospinal fluid that are specially developed to track changes in the living brain. The goal is 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 physicians can detect the disease before the person has overt memory loss," said 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 prevent or delay the memory loss from happening at all. Early diagnosis is really 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 without signs of cognitive problems can enroll in the study control group.

"By taking part in the study, those who have Alzheimer's disease in their family 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," Kerwin said.

Another important aspect of the study is the sharing of data soon after they are obtained. Imaging data are posted to a publicly accessible database available to qualified researchers worldwide.

To find out more about this study, contact project 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.

NEWS BRIEFS

CLINIC SETTLES INTO NEW HOME

The Northwestern Neurobehavior and Memory Clinic, the clinical arm of the CNADC, has seen a 50 percent increase in patient volume as its new larger space allows the staff to see more patients daily.

The clinic moved in March 2010 from the Galter Pavilion to its new home on the ninth floor of Arkes Family Pavilion at 676 North St. Clair Street in Chicago. It is now staffed by 15 providers. Behavioral neurologists, neuropsychologists, neuropsychiatrists, licensed clinical social workers, and a geriatrician provide multidisciplinary services to benefit both patients and caregivers.

The clinical space was built to CNADC's specifications to facilitate the most comprehensive, dignified, and compassionate care for persons with Alzheimer's disease and related disorders. It includes a waiting room and front-desk check-in area, six exam and testing rooms, an administrative office, and a family room used for education and supportive counseling of families accompanying loved ones to appointments.

"After a year in the new location, the clinic staff still receives compliments from patients, families, and visitors about how well designed and comfortable the clinic is," says manager Cori Malone.

Malone is one of four recently hired staff members. He started work in July 2010 after serving as a practice manager at the Rehabilitation Institute of Chicago.

Social worker Jaimie Robinson, the new resource navigator, joined the clinic after serving as a graduate intern at the CNADC and working at the Alzheimer's Association. She assists patients and families with symptom-specific ideas, interventions, and resources.

Behavioral neurology fellows Hyung Sub Shim and Joseph Cooper joined the clinic after completing their medical residencies, Shim at the University of Iowa Hospital and Clinics and Cooper at the University of Chicago Medical Center.

CAMRI EXPANDS SPACE, FACILITIES, AND PERSONNEL

New space, facilities, faculty, and staff at its Center for Advanced Magnetic Resonance Imaging (CAMRI) help the CNADC remain among the elite aging and dementia research centers. Neuroimaging provides crucial information on the mechanisms of the various dementias, accurate diagnosis, and non-invasive ways of monitoring outcomes in clinical trials.

CAMRI, an essential resource for CNADC research projects, began in 2002 under the direction of Todd Parrish, associate professor of radiology in the Feinberg School. Starting with 1.5T and 3T magnets in 4,500 square feet of space in the basement of Olson Pavilion, it doubled its space and number of magnets in 2010.

Thanks to two high-end instrumentation grants, CAMRI now has a 7T animal magnet (with a six-inch bore) and a 3T Skyra magnet for cardiovascular research. In addition, the Feinberg Department of Psychiatry provided funds to expand CAMRI's space to more than 11,000 square feet and to purchase a Siemens 3T Trio magnet, a twin of the original 3T magnet. The new space focuses on adolescent psychiatric disease and CNADC-related projects.

Also expanding CAMRI's technological capability are a new stereotactically guided Nexstim TMS system and a 64-channel EEG suite that can be used as an auditory testing booth. CAMRI has added three full-time technologists, two nurses, and an administrator for these additions.

CAMRI has three research assistant professors to support studies. Xue Wang's expertise is in signal processing, data analysis, and paradigm programming. She has experience with the MR-compatible EEG system. Daniel Procissi, director of the 7T animal system, came from the California Institute of Technology with experience imaging many animal models, from the nonhuman primate to the mouse. Jennie Chen joined CAMRI as operational manager in March. She was a graduate student in the Department of Biomedical Engineering working with Parrish, and she finished a University of Pennsylvania postdoctoral study of brain perfusion using arterial spin-labeling methods. She has expertise in data collection, pulse sequence programming, and data processing.



The original CAMRI space is shown in pink (upper right). The new areas are the 7T animal magnet space (light blue), the Trio magnet space with TMS and EEG (orange), and the 3T magnet space (dark blue).

FIRST MENDELSON LECTURE DELIVERED DURING ALZHEIMER DAY

Geriatric neurologist and researcher Claudia Kawas of the University of California, Irvine, delivered the first annual Mendelson Lecture



Barry Petersen and Claudia Kawas

during Alzheimer Day May 5.

Her topic was “Lessons from the Oldest Old: The 90+ Study.”

More than 250 guests attended the 17th annual Alzheimer Day in Northwestern’s Feinberg Pavilion.

A scientific poster session following the lecture showcased 43 posters from Northwestern researchers in aging and dementia.

The Marie and Carl Duncan Prize in Memory Research went to Carmen Westerberg for her poster “Electrically Enhancing Memory Consolidation during Sleep: A Novel Method for Reducing Age-Related Memory Decline.”

Northwestern journalism alumnus Barry R. Petersen, a CBS News correspondent and author of *Jan’s Story: Love Lost to the Long Goodbye of Alzheimer’s*, concluded the day with a moving presentation. He shared his story about caring for his wife, Jan, who was diagnosed with younger-onset Alzheimer’s disease at age 55. Diana Kerwin, an assistant professor of medicine at the Feinberg School; CNADC social worker Mary O’Hara; and Pati Hoffman, who has younger-onset Alzheimer’s disease, joined Petersen in an informative town hall-style discussion period following the talk.

The 18th annual Alzheimer Day will be Thursday, May 10, 2012.

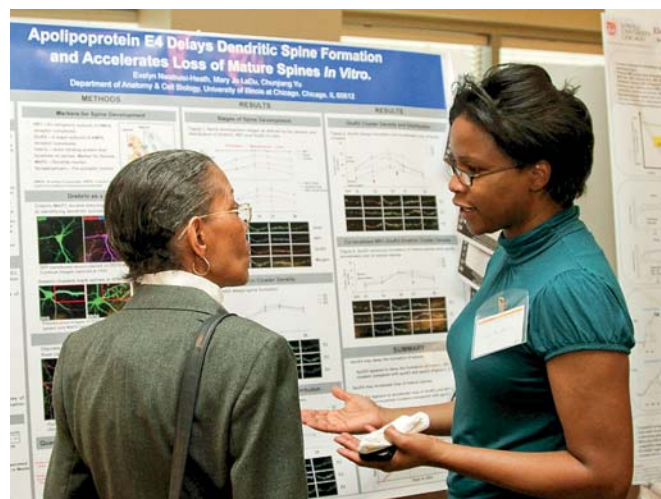
The CNADC is grateful to the Mendelson family for sponsoring the annual Mendelson Lecture. Linda and Bob Mendelson are founding members of the CNADC’s Community Advisory Board and in 1994 established the Mendelson Fellowship for postdoctoral students in neurology and neuropsychology.



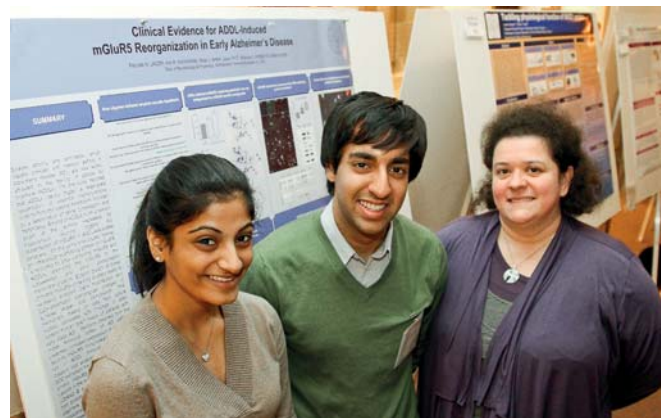
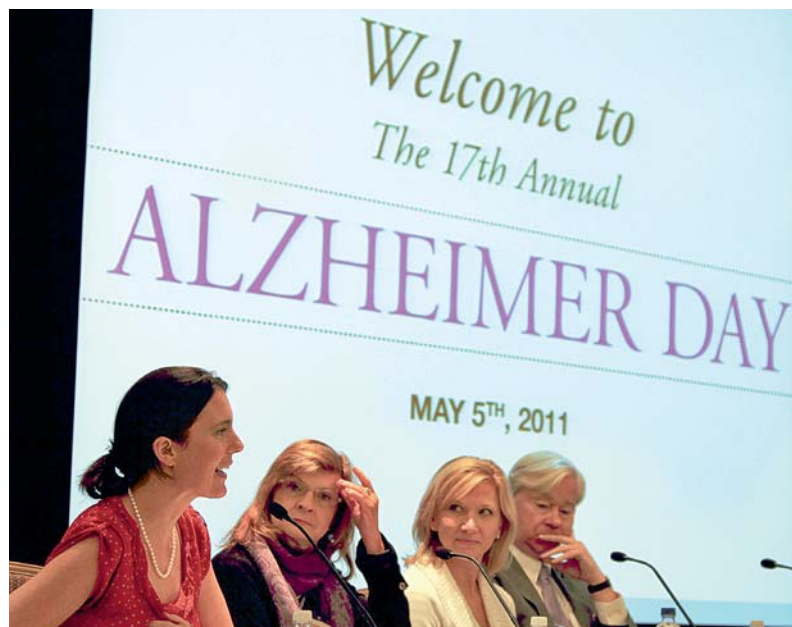
Bob (left), David (center), and Linda (right) Mendelson with (back right) Sharon (Mendelson) Markman and (center) Claudia Kawas



Town hall panel speakers (from left) Mary O’Hara, Pati Hoffman, and Diana Kerwin



Poster presenter Evelyn Nwabuisi (right) discussing her work with attendee Francine Davis



Poster presenters (from left) Niral Shah, Anil Wadhvani, and Pascale Lacor

NEWS BRIEFS

Mesulam Receives Alzheimer's Association Award

The Alzheimer's Association has recognized **CNADC director M.-Marsel Mesulam** with the **Bengt Winblad Lifetime Achievement Award** for his extraordinary achievements in advancing Alzheimer research. The award was presented at the 2010 International Conference on Alzheimer's Disease in Honolulu.

Mesulam's research addresses the connectivity of the monkey brain, the organization of human cholinergic pathways, the representation of human cognitive functions in large-scale neurocognitive networks, and the neurobiology of dementias. His work on cholinergic pathways has been groundbreaking in understanding Alzheimer's, and he is a world expert on primary progressive aphasia.

Mesulam was born in Istanbul in 1945. He received BA (1968) and MD (1972) degrees from Harvard University. He became a professor of neurology at Harvard Medical School and founded and led the Behavioral Neurology Unit of Boston's Beth Israel Hospital. In 1994 he joined Northwestern as Ruth and Evelyn Dunbar Professor of Neurology, Psychiatry, and Psychology at the Feinberg School and director of the multi-departmental CNADC.

"I'm Here with Hope" —MEMORY WALKER PATI HOFFMAN

Editor's note: In September 2010 the CNADC again joined the Alzheimer's Association—Greater Illinois Chapter in the annual Memory Walk in Chicago. The association asked the center whether one of its early-stage support group participants would be willing to speak before the walk about living with Alzheimer's disease. Pati Hoffman eloquently shared her thoughts and reflections and has generously given permission for them to be reprinted here.



Pati Hoffman (center) with other participants in Memory Walk

I should not be here this morning.

You should not be here this morning.

We should be tucked away in our beds thinking about how great the day will be. Planning our afternoon with family and friends.

But we are here, and we are here for a reason.

Almost a year ago, I was diagnosed with early-onset Alzheimer's. It took three MDs, several PhDs, and untold specialists. It took a year of confusion, a year of persistence, and a year of pain. (And I'm still trying to get my insurance to pay the bill for the test that diagnosed the disease.)

The effort to find a diagnosis was not easy—nor was it pleasant. There was little support or compassion from my employer. There was little understanding of the confusion I was going through—even now—from those I'm closest to. There was initial denial from my family.

But I'm here today, and I'm here with hope.

I have hope because there are efforts being made to find the cause and cure for this devastating disease. I'm hopeful that it will happen in time for me, and I'm hopeful that it will happen in time for you and yours.

I even have hope because many of those memory jokes really are funny—if I could just remember them.

How will this cure happen?

It will happen when more of us get involved, show our numbers, and talk to our families and friends.

It will happen when we achieve greater publicity for and understanding of the disease.

It will happen when we accomplish greater contributions for research towards finding the cause.

It will happen when the government gets behind a push for a cure.

It will happen because you will make it happen!

I think the Chinese saying applies here, especially this morning: A journey of a thousand miles starts with a single step. Let's take that step this morning. Come walk with me.

Hello!

MEET THE CNADC STAFF



Megan Atchu is a research administrator at the CNADC. Her main responsibility is the day-to-day management of grants. She also

supports the advisory board in fundraising and development activities. She received a BS from the Krannert School of Management at Purdue University and is working on an MA from Northwestern in public policy and administration.



Alejandra Balen works closely with Sandra Weintraub and Mallory Swift as a research coordinator in the Clinical Core. Balen

joined the CNADC from a volunteer position at Children's Memorial Hospital. A recent graduate of the University of Michigan with a BA in psychology, she worked there as a research assistant in the Department of Psychology and Neuroscience. She is proficient in Spanish and French and spent the summer of 2009 in Popayan, Colombia, as a surgical assistant.



Kevin Connolly, CNADC business administrator, is responsible for financial management and business operations. He has more than 10 years of

business administration experience and specializes in higher education administration. He has worked in the health sciences field at higher education institutions for more than six years, most recently at the University of Illinois at Chicago. He received a BS in marketing from Illinois State University.



Joseph Cooper is a neuropsychiatry and behavioral neurology fellow. He received his undergraduate degree in neuroscience from Johns

Hopkins University and completed medical

school and a residency in psychiatry at the University of Chicago. He specializes in the clinical care of patients with both neurologic and psychiatric conditions. His research interests include investigating the role of neuropsychiatric symptoms in Alzheimer's disease.



Cori Malone is manager of the Neurobehavior and Memory Clinic. He previously was physician practice manager at the Rehabilitation Institute

of Chicago. His past experience also includes interning at the AIDS Foundation of Chicago and the American Cancer Society. He received a BA from the University of Illinois at Urbana-Champaign and an MA in social work and health administration from the University of Chicago.



Jaimie Robinson is coordinator of the Resource Navigator and the Young Onset Program. She assists patients and families with

symptom-specific ideas, interventions, and resources. She received an MSW from Loyola University Chicago, where she was awarded the Hartford Geriatric Fellowship. She was a graduate social work intern at the CNADC from 2007 to 2008 and returned after working two years at the Alzheimer's Association national office.



Hyung Sub Shim is a behavioral neurology fellow. He holds the Rosenstone Fellowship, established in memory of the late Jerome

Rosenstone, founder and first chair of the CNADC Community Advisory Board. He earned a medical degree at the Medical College of Wisconsin and did a neurology residency at the University of Iowa. His clinical and research interests are in language and aphasia.



Saman Seyedahmadian is a postdoctoral fellow from Tehran who works in Changiz Geula's laboratory. The exposure to advanced research

techniques there will enhance his future practice in neurological care. He was a research consultant at one of Tehran's best psychiatric hospitals, Roozbeh, after graduating from Iran University of Medical Science with honors.



Kristine Zachrich is a research study programs coordinator and helps with patient programs such as the Memory Ensemble and Buddy

Program. She received a BS in communication disorders from Bowling Green State University in 2008.

Giving Opportunities

The research and clinical services of the CNADC and the Neurobehavior and Memory Clinic depend on both public and private resources. Funds come from competitive grants from the National Institutes of Health, foundation-sponsored programs, and individual gifts and bequests from patients, families, friends, and corporate and other benefactors. We are especially appreciative of gifts in these harsh economic times.

While NIH funding supports the basic infrastructure of the center, your donations and bequests allow us to pursue and sustain new and innovative efforts in clinical research and caregiving support. Individual, family, and corporate giving is essential to our ongoing efforts to understand and treat disabling conditions.

Please consider supporting us. There are many ways to make gifts in honor of or in memory of an individual.

If you have questions or would like to discuss a giving option, please contact senior associate director of development

Barbara Monroe at **312-503-0761** or **barbaramonroe@northwestern.edu**.

Congratulations

The CNADC extends congratulations to three students and a faculty member who have received funding for their research:

Clinical neuropsychology PhD students **Julia Rao** and **Tamar Gefen** have received predoctoral traineeships from the Neuroscience of Human Cognition Training Grant Program of the National Institutes of Health for their research on superaging, a high level of cognitive functioning after age 80. Rao's dissertation focuses on the personality and brain structural factors that contribute to superagers' high cognitive functioning. She will analyze personality profiles as well as tissue volumes in the hippocampus and amygdala, brain structures that have been linked to emotional processing, episodic memory, and Alzheimer's disease. Gefen's research will investigate from a multi-disciplinary approach the factors that differentiate supernormal and normal aging. She intends to examine the cingulate gyrus—an area of the brain responsible for attention, motivation, and memory—by looking at cognitive performance, brain imaging, and postmortem tissue.

Rob Hurley, a CNADC postdoctoral student, received a Mechanisms of Aging and Dementia Training Grant, an institutional NIH award for graduate students and post-docs interested in aging and dementia. The training grant includes a stipend, partial tuition, and funds for training seminars and travel. John Disterhoft, Magerstadt Memorial Research Professor in the physiology department, is the principal investigator. The grant also supports a team-taught course in which specialists give weekly lectures on subtopics of aging and dementia.

Emily Rogalski, research assistant professor at the CNADC, received a KL2 Award from the Northwestern University Clinical and Translational Sciences Institute for her work on PPA using neuroimaging with structural MRI scans to examine brain-behavior correlations. Her findings have resulted in the ability to detect unique areas of cortical thinning within the network associated with different aspects of language. Rogalski's work also examines the rate of disease progression and underlying pathology by synthesizing longitudinal quantitative MRI data with neuropsychological performance; eventually these data will be linked with pathologic outcomes.



NEW FACULTY

Jennifer Medina, a clinical neuropsychologist, has joined the CNADC faculty as an instructor in the Department of Psychiatry and Behavioral Sciences. She was a graduate student at Northwestern in the neuropsychology specialty track and worked at the the CNADC from 2004 to 2009.

Her graduate clinical training focused on aging and dementia, and she has published peer-reviewed articles on depression in PPA, tools for coping with memory loss, and education and support programs for frontotemporal dementia.

Medina finished graduate study in 2009 and completed an internship in clinical psychology at Rush University Medical Center and a post-doctoral fellowship in clinical neuropsychology at the University of Illinois at Chicago.

At the CNADC she will focus on the evaluation of cognition and behavior in adults, particularly cognitive disorders affecting older adults. Her clinical interests also include the psychosocial and mood-related effects of neurological disorders on diagnosed individuals and their family members. In addition to neuropsychological assessment and nonpharmacological intervention for cognitive disorders, Medina's interests include teaching and supervision of doctoral trainees and promoting education on topics in neuropsychology and cognition.

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RESEARCH

Study Links Older Women's Brain Function to Weight

The more an older woman weighs, the worse her memory, according to new research from Northwestern Medicine. Fat may contribute to the formation of plaques associated with Alzheimer's disease or a restricted blood flow to the brain.

The study of 8,745 cognitively normal, postmenopausal women ages 65 to 79 from the Women's Health Initiative hormone trials is the first in the United States to link obesity to poorer memory and brain function in women. The study was published July 14 in the *Journal of the American Geriatric Society*.

"The message is that obesity and a higher body mass index (BMI) are not good for your cognition and your memory," said lead author Diana Kerwin, an assistant professor of medicine at the Feinberg School and physician at Northwestern Memorial Hospital and a CNADC-affiliated faculty member. "While the women's [memory] scores were still in the normal range, the added weight definitely had a detrimental effect."

The women were scored on a 100-point memory test, called the Modified Mini-Mental Status Examination. The study controlled for such variables as diabetes, heart disease, and stroke. For every one-point increase in a woman's BMI, her memory score dropped by one point. The study also identified a body shape connection: the memory effect was more pronounced in pear-shaped women, who carry excess weight around their hips, than in apple-shaped women, who carry it around their waists.

"Obesity is bad, but its effects are worse depending on where the fat is located," Kerwin said. The reason pear-shaped women experienced more memory- and brain- function deterioration than did apple-shaped women is likely related to the type of fat deposited around the hips versus the waist.

Cytokines, hormones released by the predominant kind of fat in the body that can cause inflammation, likely affect cognition, Kerwin said. Scientists already know different kinds of fat release different cytokines and have different effects on insulin resistance, lipids, and blood pressure.

"We need to find out if one kind of fat is more detrimental than the other, and how it affects brain function," Kerwin said. "The fat may contribute to the formation of plaques associated with Alzheimer's disease or a restricted blood flow to the brain."

In the meantime, the new findings provide guidance to physicians with overweight older female patients.

"The study tells us that if we have a woman in our office, and we know from her waist-to-hip ratio that she's carrying excess fat on her hips, we might be more aggressive with weight loss," Kerwin said. "We can't change where your fat is located, but having less of it is better."

Kerwin's research is funded by the T. Franklin Williams Award from Atlantic Philanthropies and the Association of Specialty Professors and by the Wisconsin Women's Health Foundation Faculty Scholar Award. The Women's Health Initiative was funded by a grant from the National Heart, Lung, and Blood Institute.

—Marla Paul, *health sciences editor, Northwestern University*

Buddy Program Thrives in Its 15th Year

Now in its 15th year, the Buddy Program continues to be the CNADC's most innovative and enriching quality-of-life program.

More than 162 buddy pairs have been matched so far through the program connecting first-year medical students with patients from the CNADC. Students from the Feinberg School of Medicine and patients in the early stages of Alzheimer's disease or related cognitive disorders are paired for mutual mentoring and companionship.



The program was designed so that the person with dementia and the student meet on equal ground. It is based on relationship, dialogue, and reciprocity. The person with dementia is given the opportunity to become a mentor for a medical student who wishes to learn outside a clinical setting how someone copes with an illness. Students often express surprise at finding that the illness does not define who people with dementia are; the courage the students see is striking. Students also learn about the emotional toll the disease takes on caregivers.

"I worry if I will be a good physician," said a 2010 buddy. "Will I be able to help everyone? Will my patients learn from me? How can I communicate with them? I believe the Buddy Program has given me a valuable experience. I have learned how to speak with patients and their families, taking into account the feelings behind the symptoms, and to put aside my own assumptions. A good doctor cures symptoms; a great doctor is able to help a patient to understand and to look forward to taking steps to improve health in both body and mind.

Sometimes, all it requires are a friendly ear and a hot cup of coffee. I am very satisfied with the Buddy Program."

Through longitudinal follow-up studies of 95 buddies, it was found that about 70 percent of the medical students went into patient-care oriented specialties, such as internal medicine, family practice, and neurology; 26 percent, into procedural-oriented practices, such as surgery, radiology, and anesthesiology; and 3 percent, into both clinical practice and basic science research.

Impressed by the program's success, other medical schools have replicated it. Four years ago Boston University Medical School's Alzheimer's Disease Center created a successful program. This past year Banner Alzheimer's Institute at the University of Arizona

College of Medicine in Phoenix and Dartmouth Medical School created programs.

A dissemination manual has been developed about Northwestern's program. It is available by e-mailing **d-morhardt@northwestern.edu**. For more information on the program, go to **www.brain.northwestern.edu/education/buddy.html**.

Northwestern's Buddy Program is supported by a grant from the Glen and Wendy Miller Family Foundation.

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RESEARCHERS AND PATIENTS USE ONLINE IMPACT RESOURCE

An online primary progressive aphasia resource, IMPACT (International PPA Connection) was developed for researchers, clinicians, people with PPA, and their families with federal stimulus funding the CNADC received in 2009 through the National Institute on Deafness and Other Communication Disorders. The centralized registry of people with PPA can be accessed at www.ppaconnection.org.



Since researchers can use it to search for research participants and to collaborate with other professionals, the resource fosters studies on PPA across centers. These users can log in and list data they have available at their own centers. They can also add PPA-specific links and advertise their own research studies. As of April, IMPACT had 280 listed subjects and 92 registered researchers from 21 countries.

IMPACT also serves as a resource for people with PPA and their families. The public can access detailed information about PPA, see a listing of support groups in their areas, find research programs, and browse links.

The CNADC hopes to further develop IMPACT and to use the site for large-scale studies on PPA.

*Member of the Northwestern Alzheimer's Disease Center Executive Committee

In Memory of Ruth Dunbar Davee, CNADC Founder

Ruth Dunbar Davee, whose major gift with her husband, the late Ken M. Davee, allowed the CNADC to be founded in 1994, died April 19 at age 99. Ms. Davee and her husband also endowed the Feinberg School's neurology department, which now bears the name Ken and Ruth Davee Department of Neurology. Ms. Davee and her sister Evelyn endowed the psychiatry department's Ruth and Evelyn Dunbar Professorship, which is currently held by CNADC director M.-Marsel Mesulam.



Ms. Davee earned both her MA (1937) and her PhD (1942, literature) at Northwestern. She taught at the Polytechnic Institute (later Inter American University) in Puerto Rico. While there, she coauthored *Remedial English for Spanish-Speaking Students*, which was a standard textbook in classrooms for many years.

She then took a reporting job at the *Chicago Sun-Times*. Her 1955 series of in-depth stories about how schools teach reading, "Why Johnny Can't Read—Or Can He?," was so groundbreaking that the *Sun-Times* sold more than 50,000 copies and reprints. It earned Ms. Davee the 1955 Marshall Field Award and the Education Writers Association Award. Another series, 11 articles on her trip to the USSR to research its education system, earned the School Bell Award in 1959.

In 1960 Ms. Davee received Hall of Fame recognition from B'nai B'rith Women's Council of Greater Chicago for her contribution "to the building of a great American city." In 1965 she was honored with the annual Good American Award for making outstanding contributions within the field of human relations and for practicing the basic principles of American democracy.

After retiring from the *Sun-Times*, she became assistant director of the Illinois Department of Education, managing the federally sponsored Title One program. After retiring, Ms. Davee did consulting work in writing, including a book on Egyptology for the University of Chicago.

In 1988 she married business entrepreneur and philanthropist Ken Davee. Upon his death in 1998, she took over as president of the Davee Foundation. She was a member of the CNADC Advisory Board until her death.

Ms. Davee traveled to more than 100 nations and wrote thousands of pages documenting the social, economic, and cultural lives of many peoples.

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RUN 4 PAPA



In honor of his grandfather and all others affected by PPA, Jason Boschan of Charlotte, North Carolina, has partnered with the CNADC to raise at least \$50,000 to support PPA awareness and research. He intends to create awareness nationally and internationally and to raise the money

by running in the 2012 Great Wall Marathon in China's Tianjin Province in May.

Jason's grandfather, Dr. Louis "Papa" Heyman, a pediatrician in West Bloomfield, Michigan, recently gave up a 50-plus-year practice after his diagnosis with PPA. As he has made the difficult adjustment, Heyman was thrilled and proud to hear about his grandson's plans. Boschan recently launched the website www.run4papa.com, which includes his training regimen, his grandfather's biography, information about PPA, and progress toward his fundraising goal.

Boschan hopes to visit Chicago and the CNADC in February 2012 to run the Hustle Up the Hancock race, a 94-floor climb of the John Hancock Building, as part of his training for the Great Wall Marathon.

If you are interested in supporting Boschan's cause, make a secure online donation at www.giving.northwestern.edu/nu/CNADC. All proceeds will go directly toward PPA research and education.

UPCOMING EVENTS

Alzheimer's Disease Seminar Series

Moving to monthly for 2011-12 academic year.

See schedule at www.brain.northwestern.edu/events/future_seminars.html.

FTD/PPA Caregiver Education and Support Conference

Saturday, March 24, 2012, 8:30 a.m.-4:30 p.m.

18th Annual Alzheimer Day

Thursday, May 10, 2012, 11:30 a.m.-4 p.m.

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