# BUADC Bulletin

BOSTON UNIVERSITY ALZHEIMER'S DISEASE CENTER FUNDED BY THE NATIONAL INSTITUTE ON AGING

# Discussion Groups for African Americans

A frican Americans participate in medical research at much lower rates than their White peers both nationally and locally at the Boston University Alzheimer's Disease Center (BU ADC). This disparity has important and potentially serious implications for the African American community because research findings may not apply to African American elders if they are underrepresented in studies. The BU ADC recognizes this problem and is committed to minimizing the gap by increasing African American elder participation in research.

The BU ADC Education & Information Transfer Core (EITC) is pleased to announce the launch of a brand new project intended to minimize research participation disparities between African American and White elders. Thanks to feedback from focus groups with fifteen African American HOPE participants held in the summer of 2008 and seven African American HOPE participants held in the winter of 2009, the EITC has developed a culturally relevant group discussion guide centered on African Americans, research, and Alzheimer's disease (AD). The goal of the group discussion is to provide important information about how AD affects the African American commu-*Discussion Groups continued on page 3* >



Group participants Helen Young (left) and Barbara Gumes (right) with African American Outreach Coordinator Dorothy Marshall (center).



SPRING 2010 volume 9, issue 1

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### What's the Difference Between Alzheimer's and Dementia?

Too often, patients and their family members are told by their doctors that the patient has been diagnosed with "a little bit of dementia." They leave the doctor's visit with a feeling of relief that at least they don't have Alzheimer's disease (AD). There is great confusion about the difference between "dementia" and "AD." The confusion is felt on the part of patients, family members, the media, and even healthcare providers. This article provides information to reduce the confusion by defining and describing these two common and often poorly understood terms.

"Dementia" is a term that has replaced a more out-of-date word, "senility," to refer to cognitive changes with advanced age. Dementia includes a group of symptoms, the most prominent of which is memory difficulty with additional problems in at least one other area of cognitive functioning, including language, attention, problem solving, spatial skills, judgment, planning, or organization. These cognitive problems are a noticeable change compared to the person's cognitive functioning earlier in life and are severe enough to get in the way of normal daily living, such as social and occupational activities.

A good analogy to the term dementia is "fever." Fever refers to an elevated temperature, indicating that a person is sick. But it does not give any information about what is causing the sickness. In the same way, dementia means that there is something wrong with a person's brain, but it does not provide any information about what is *Alzheimer's and Dementia continued on page 3* >

## "I Remember Better When I Paint"

The Boston University Alzheimer's Disease Center (BU ADC) hosted the Boston premiere screening of "I Remember Better When I Paint" on January 12, 2010. The film by Eric Ellena and BU ADC Board member Berna Huebner, and narrated by actress Olivia de Havilland, is the first international documentary about the positive impact of art and other creative therapies on people with Alzheimer's disease (AD). It examines the way creative arts, such as painting or museum visits, can transcend the cognitive limitations of AD and other dementia disorders and allow patients an outlet to exercise their intact imaginations.

The concept for the documentary was inspired by Huebner's mother, famous artist Hilda Goldblatt Gorenstein, known professionally as Hilgos.



Suffering from the advanced stages of AD, Hilda was apathetic and non-communicative, until one day her daughter asked, "Mom, do you want to paint?" to which Hilda surprisingly replied, "Yes, I remember better when I paint." With the encouragement of her family and visiting art students, Hilda started painting again, and her mood and speech soon began to improve. Hilda eventually created over 300 paintings during her final years in a nursing home.

The documentary includes interviews with renowned clinicians who explain how creative activities engage areas of the brain that are not damaged by AD and thus reawaken a sense of personality, identity, and dignity in patients. Among those clinicians featured in the documentary were BU ADC faculty members, Drs. Robert Green and Robert Stern. The film also features Yasmin Aga Khan, president of Alzheimer's Disease International and daughter of Rita Hayworth, who suffered from AD before dying in 1987. Other prominent members of the field are featured in the film, advocating for increased use of creative therapies in adult day programs, nursing homes, and assisted living facilities.

Following the film screening, the BU ADC presented a panel discussion and took questions from the audience of more than 300 attendees. Panel members included: BU ADC faculty members Drs. Brandon Ally, Robert Green, and Robert Stern; Meg Curtis, who is married to BU ADC participant Charles "Skip" Curtis, who was



featured in the film; President and Co-Founder of Hearthstone Alzheimer Care and the I'm Still Here Foundation, Dr. John Zeisel; and the film's Co-Director and Producer, Berna Heubner. The group discussed current research and development of AD treatments, emphasizing the importance of creative therapeutics in achieving comprehensive care and improving quality of life.

"I Remember Better When I Paint" is presented by French Connection Films and the Hilgos Foundation. For more information about this film and additional projects supporting artistic creation in elderly populations, please visit the Hilgos Foundation website at www.hilgos.org. For those interested in viewing the film, "I Remember Better When I Paint" is now available on DVD and can be purchased online at amazon.com.

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nity and to increase African American enthusiasm for and participation in medical research projects.

The development and implementation of the group discussion guide specifically for African Americans is one major effort by the BU ADC to put prior focus group feedback into practice. Dorothy Marshall, a recent addition to the BU ADC staff, will lead the new discussion groups. Ms. Marshall serves as the BU ADC African American Outreach Coordinator, and she is a candidate for a master's degree at the BU School of Public Health with interests in health communication and racial disparities. The discussion groups and Ms. Marshall's new position are funded by a special supplement grant awarded to Dr. Angela Jefferson, EITC Director, and the BU ADC as a part of the American Recovery and Reinvestment Act of 2009. Dr. Jefferson states, "This innovative project has the capacity to foster significant improvement in an area of disparity that needs our attention. We are delighted that the National Institute on Aging is committed to putting the necessary financial resources behind our efforts."

The group discussion content covers topics that prior focus group participants identified as most relevant to African American elders. First, it presents an opportunity for African American HOPE participants to discuss and share ideas, concerns, and questions with their peers and the group leader. The discussion addresses barriers that prevent some African Americans from being involved in research, while showing why active participation in research is important and essential to the African American community as well as the scientific community at large. Second, it provides an opportunity for participants to learn more about AD and related research and ask questions about AD risk factors and prevention. Finally, it provides resources for those HOPE participants who want to get more involved or learn more about the services and research opportunities available at the BU ADC.

The first group discussion was held in January with seven HOPE participants and family members, and the feedback so far has been positive. Ms. Helen Young, a HOPE participant for seven years, states, "The discussion was useful, and I learned a lot of new information. A lot of good ideas were thrown around about how to get information out to the African American community. We were able to share our thoughts and ideas with other people in the group." Her sister, Ms. Barbara Gumes, also a HOPE participant for seven years, states, "I really enjoyed the conversation. I enjoyed meeting other people in the group. The discussion made my mind more settled about what happens when you get older. This is important information for people to hear." Dorothy Marshall, the group's facilitator, is excited about the opportunity to hold additional groups and talk with HOPE participants about AD and research participation. She says, "I think that if people knew the impact they have when they get involved in research, participation rates would increase."

Group discussions for African American HOPE participants are being held monthly. If you are an African American HOPE Study participant and you are interested in joining an upcoming group, please contact Dorothy Marshall at 617-414-8385 or dmarsh@bu.edu.

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causing the memory or cognitive difficulties. Dementia is not a disease; it is the clinical presentation or symptoms of a disease.

There are many possible causes of dementia. Some causes are reversible, such as certain thyroid conditions or vitamin deficiencies. If these underlying problems are identified and treated, then the dementia reverses and the person can return to normal functioning. However, most causes of dementia are not reversible. Rather, they are degenerative diseases of the brain that get worse over time. The most common cause of dementia is AD, accounting for as many as 70-80% of all cases of dementia. Approximately 5.3 million Americans currently live with AD. As people get older, the prevalence of AD increases, with approximately 50% of people age 85 and older having the disease. It is important to note, however, that although AD is extremely common in later years of life, it is not part of normal aging. For that matter, dementia is not part of normal aging. If someone has dementia (due to whatever underlying cause), it represents an important problem in need of appropriate diagnosis and treatment by a well-trained healthcare provider who specializes in degenerative diseases.

In a nutshell, dementia is a symptom, and AD is the cause of the symptom. When someone is told they have dementia, it means that they have significant memory problems as well as other

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### Actively Recruiting Studies Study Type Study Title Study Description

BU ADC Research Registry	Health Outreach Program for the Elderly (HOPE)	This longitudinal study examines age-related changes in memory and thinking. It serves as the Boston University Alzheimer's Disease Center (BU ADC) research registry, where participants agree to be contacted about other BU ADC-approved studies. HOPE participants are encouraged to participate in the actively recruiting studies summarized below.
Caregiving Support & Education	CARE-Plus	This study examines whether an educational intervention with caregivers can reduce behavioral problems in Alzheimer's disease (AD) patients and improve caregivers' well- being. Participation includes a 5-week intervention with weekly sessions on AD and tips to improve interactions. The individual diagnosed with AD is not involved in this study.
	Education about MCI *new study	This study provides adults with mild cognitive impairment (MCI) and their study part- ners information about MCI and the risks of developing AD. Study results will be used by clinicians and researchers to evaluate the impact of the educational program. The study involves four in-person visits and one phone call over the course of 6 months.
	Health Pathways	This study looks at how caregiving affects one's physical and emotional health among caregivers age 60 and older who currently provide care for someone with AD. Participants attend four yearly face-to-face interviews where they will be asked questions about their health and about the person they care for.
	PAIRS Program	This program pairs first-year Boston University medical students with patients who have early-stage AD. The program educates medical students about the care and support-related issues faced by patients with AD. Student-patient pairs meet monthly to participate in social activities throughout the academic year.
Early Detection	RETINA Study *new study	This study uses routine ophthalmological tests to detect biomarkers that predict the onset of AD. The study includes one visit to the Massachusetts Eye and Ear Infirmary. Participants must be enrolled in the HOPE Study and will need a study partner who can accompany them to study visits. Study participation is for cognitively normal adults or persons with MCI or AD, age 50 and older.
Evaluation of Daily Living	Functional Assessment in Dementia	This study investigates the relationship between office-based cognitive tests and inde- pendent functioning in the home. Individuals with dementia, who are not living in an assisted living facility or nursing home, may be eligible to participate.
	SAFE Drivers	This study aims to develop a brief, office-based evaluation of driving safety for older drivers that accurately predicts on-road driving performance. Study participation is for older drivers with or without memory problems between 55 and 90 years of age. Two study visits involve office-based cognitive tests and an on-the-road driving evaluation conducted by a certified driving instructor.
Memory & Cognition	False Memory in AD	This study seeks to understand why patients with AD and other dementias frequently remember things that never happened. The goal of this study is to provide ways to reduce false memories in patients with dementia.
	Vision & Cognition	This study examines visual change in AD, how it affects cognition and daily activities, and how visual interventions may improve cognitive abilities. Participants perform tests of vision, cognition, and daily functions, and a free eye exam is included. Study participation is for adults age 50 or older with a diagnosis of mild to moderate AD.
Neuroimaging	Heart & Brain Aging	This study uses heart and brain imaging and memory tests to better understand rela- tions between heart and brain health among aging adults with mild memory loss, par- ticularly those individuals who have been diagnosed with MCI. Participants receive feedback about heart and brain health, and results are shared with the participant's physicians.

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### **Actively Recruiting Studies** < *continued from page 4* Study Type Study Title Study Description

	Alzheimer's Disease Neuroimaging Initiative	This study uses magnetic resonance imaging, positron emission tomography, and amyloid imaging to determine whether imaging of the brain can help predict the onset and monitor the progression of cognitive change. Researchers are looking for persons between 55 and 90 years of age and who are in good general health but have memory problems or concerns.
Treatment	CONCERT	This multi-center treatment trial will evaluate a new oral medication, Dimebon. Dimebon may stabilize unhealthy changes in brain cells in individuals with mild or moderate AD. Participants must be 50 years of age or older and need a study partner to accompany them to study visits.
	IDENTITY	This multi-center treatment trial will evaluate if an oral medication, "LY450139," can slow the progression of mild or moderate AD. This new compound attempts to reduce amyloid beta (Abeta) in the brain, which has been linked to AD. Study participation is for adults over 55 years of age with a diagnosis of AD.
	Investigational Clinical Amyloid Research in AD (ICARA)	This multi-center treatment trial will evaluate whether a new medication, Bap- ineuzumab, increases the clearance of Abeta from the brain. Abeta is believed to be the initial cause of AD. This treatment study is for adults 50-89 years of age with an AD diagnosis. Participants will need a study partner to accompany them to study visits.
	Vitamin E and Memantine in AD *new study	This multi-center clinical trial will evaluate the combination of memantine and Vitamin E in the treatment of mild to moderate AD. Memantine has been shown to improve function and cognition in late stages of AD, while Vitamin E has been found to delay the progression of AD. The study is only open to veterans with a diagnosis of mild or moderate AD. Participants need a care- giver to accompany them to all visits.

For more information, please contact the BU ADC Outreach & Recruitment Coordinator, Silvia Serrano, at 617-414-1078 or sserrano@bu.edu.

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cognitive difficulties, and that these problems are severe enough to get in the way of daily living. Most of the time, dementia is caused by the specific brain disease, AD. However, some uncommon degenerative causes of dementia include vascular dementia (also referred to as multi-infarct dementia), frontotemporal dementia, Lewy Body disease, and chronic traumatic encephalopathy. Contrary to what some people may think, dementia is not a less severe problem, with AD being a more severe problem. There is not a continuum with dementia on one side and AD at the extreme. Rather, there can be early or mild stages of AD, which then progress to moderate and severe stages of the disease.

One reason for the confusion about dementia and AD is that it is not possible to diagnose AD with 100% accuracy while someone is alive. Rather,

AD can only truly be diagnosed after death, upon autopsy when the brain tissue is carefully examined by a specialized doctor referred to as a neuropathologist. During life, a patient can be diagnosed with "probable AD." This term is used by doctors and researchers to indicate that, based on the person's symptoms, the course of the symptoms, and the results of various tests, it is very likely that the person will show pathological features of AD when the brain tissue is examined following death. In specialty memory clinics and research programs, such as the BU ADC, the accuracy of a probable AD diagnosis can be excellent. And with the results of exciting new research, such as that being conducted at the BU ADC, the accuracy of AD diagnosis during life is getting better and better.

*This contribution was made by Dr. Robert Stern, Director of the BU ADC Clinical Core.* 

### **Research Updates**

# Activities of Daily Living in Mild Cognitive Impairment

**Dr. Angela Jefferson** and colleagues recently investigated relations between brain magnetic resonance imaging markers of cerebrovascular disease and Alzheimer's disease (AD) in individuals with mild cognitive impairment (MCI). Preliminary findings from the Heart & Brain Aging Study suggest increased white matter hyperintensities, but not hippocampal volume, are associated with worse functional status. These findings, which were presented at the recent International Neuropsychological Society meeting, are consistent with evidence that executive dysfunction, rather than memory impairment, is associated with functional decline and conversion from MCI to AD.

### **Blood Pressure Treatment and Dementia Prevention**

Dr. Benjamin Wolozin recently published a study in *British Medical Journal* showing that combined use of two blood pressure medications that prevent angiotensin signaling (that is, angiotensin receptor blockers and ACE inhibitors) is associated with a 50% lower incidence of dementia and, for those with dementia, a 70% lower rate of nursing home admission. Previous studies indicate that angiotensin receptor blockers are particularly effective at preventing vascular damage induced by amyloid  $\beta$ , a protein that accumulates in AD. Dr. Wolozin's findings suggest that this combination of blood pressure medications protects against cognitive decline by reducing neuronal damage associated with vascular dysfunction and stroke.

# "I know what you told me, but this is what I think"

**Dr. Robert Green**, Erin Linnenbringer, MS, CGC, and the REVEAL Study Group recently published a study in *Genetics in Medicine* evaluating AD risk perceptions among individuals who accurately recalled their genetic-based risk assessment. As part of the REVEAL Study, 246 unaffected relatives of individuals with AD were given a genetics-based risk assessment for AD. Out of 158 individuals who accurately recalled the risk assessment they were given by study investigators, nearly half believed their actual risk was different than what they had been told. These results indicate that individuals who are able to accurately recall their risk assessment do not necessarily take communicated risk estimates at face value.

# Impact of AD Genetic Risk Disclosure on Dietary Supplement Use

**Dr. Robert Green**, Dr. Jacqueline Vernarelli, and the REVEAL Study Group recently published a study in the *American Journal of Clinical Nutrition* on the impact of risk disclosure for AD on dietary supplement use. They

found that after receiving a risk assessment for AD, 16% of all participants in the study reported a change in dietary supplement use. Individuals who learned they carry the AD risk-increasing apolipoprotein (APOE)  $\epsilon$ 4 genotype were more likely to report an increase in dietary supplement use than those who learned they were APOE  $\epsilon$ 4-negative.

### Late-Life Depression and AD

It is well-known that APOE  $\varepsilon$ 4 is a major genetic risk factor of late onset AD. However, 50% of AD patients do not carry APOE  $\varepsilon$ 4, suggesting other risk factors in the pathogenesis of AD. Using a homebound elderly population in the Boston area, Dr. Wendy Oiu and her research team have found that non-APOE  $\varepsilon$ 4 carriers with depression have similar biomarkers in their blood (for example, low A $\beta$ 42 and a high A $\beta$ 40/A $\beta$ 42 ratio in plasma) as APOE £4 carriers. Because a high percentage of these depressed elderly individuals have cognitive impairment, the researchers hypothesize that amyloidassociated depression defined by low plasma AB42 and high plasma A $\beta$ 40 might be a prodromal stage of AD even in the absence of APOE  $\varepsilon$ 4. The finding was recently published in Alzheimer's Disease & Associated Disorders and may offer an additional target for the prevention and intervention of AD. Dr. Qiu has received an R01 grant from the National Institute on Aging to further study the relationship between late-life depression and AD.

### **Community Action Council**

The Boston University Alzheimer's Disease Center (BU ADC) Community Action Council (CAC) met on March 18, 2010. The group discussed a new program from the Alzheimer's Early Detection Alliance focused on outreach to African American families and churches and a new location-tracking product from the Alzheimer's Association called Comfort Zone. The CAC meets bimonthly to share information about upcoming events, research, and new developments related to Alzheimer's disease.



BU ADC Director, Dr. Neil Kowall (left), and Community Action Council members at the March 2010 meeting.

### **BU ADC Happenings**

#### Welcome

The Boston University Alzheimer's Disease Center (BU ADC) extends a warm welcome to new staff members: Meenakshi Chivukula, psychometrician for the Health Outreach Program for the Elderly (HOPE) Study; Erin Klopfenstein, senior research coordinator and assistant to Dr. Robert Green; Dorothy Marshall, the new BU ADC African American Outreach Coordinator; and Adrienne Robinson, research assistant to Dr. Angela Jefferson and the BU ADC Education & Information Transfer Core (EITC).

#### Congratulations

BU ADC EITC co-investigator, Kathy J. Horvath, PhD, RN, recently received funding to conduct a clinical translation study entitled *Implementation* of the Evidence-based New York University (NYU) Caregiver Intervention for Dementia Family Caregiver Support. Developed in collaboration with Mary Mittelman, DPh, EITC Director at the NYU ADC, the study is funded by the Department of Veterans Affairs (VA) for two years. The goal of the project is to implement an evidence-based dementia caregiver support program in two VA settings and evaluate strategies necessary to add this intervention to clinical services.

Congratulations to Dr. Andrew Budson, who assumed the position of Deputy Chief of Staff at the Boston VA Healthcare System on March 1st. Dr. Budson formerly served as the Director of the Geriatric Research, Education, and Clinical Center (GRECC) at the Edith Nourse Memorial Veterans Hospital in Bedford, MA. Congratulations to Dr. Peter Morin, who has been appointed GRECC Director at the Edith Nourse Memorial Veterans Hospital.

Congratulations to Dr. Robert Stern, who was appointed as the BU ADC Clinical Core Director on April 1st. Dr. Stern replaces Dr. Robert Green, who stepped down to devote more time to his expanding original research program in gene discovery and genetic risk assessment in AD. Dr. Green will continue in his leadership role as the BU ADC Associate Director.

Congratulations to Dr. Angela Jefferson, who was recently asked to fill a vacated term on the Education and Information Transfer Core Steering Committee for the National Alzheimer's Coordinating Center. Dr. Jefferson will hold the position through fall of 2011.

#### Goodbyes

Many thanks and best wishes to ADC staff member Natalie Joffe, who recently left the HOPE Study to pursue a position in cancer advocacy in Seattle, WA.

Thank you and best wishes to our recent student trainees: Michael Dombek, who completed dual bachelor's degrees in biology and human physiology at Boston University and is currently applying to medical school; and Brittany Masatsugu, who completed her master's degree in psychology at Boston University and has left to pursue career opportunities on the west coast.

### **Honorary and Memorial Contributions**

The Boston University Alzheimer's Disease Center (BU ADC) is involved in a variety of clinical, research, and educational activities. These activities are funded by grants awarded from the National Institutes of Health and non-profit organizations. Often, research study participants, families, or community leaders wish to contribute to the fight against Alzheimer's disease (AD), and these private donations are equally important to advancing the BU ADC's mission. The BU ADC welcomes honorary and memorial donations, as these gifts are an excellent way to pay tribute to a family member or friend while making a contribution to the advancement of research in the field of AD. Please call Harriet Kornfeld at 617-638-5676 or visit us online at www.bu.edu/alzresearch if you would like to make a donation. The BU ADC would like to recognize the following private donors for their greatly appreciated contributions:

**In honor of Sylvia Byorkman** Adele A. Madden

**In memory of Benjamin Chinitz** David Bunis Barry Brooks

**In honor of Michael Chinitz** Ben Marsh Kim and Thomas Wendt Elizabeth Ramos

**In memory of Helen Klein** Stephen Klein **In memory of Kenneth M. Lumsden** Kristina Lumsden

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**In memory of Morris Trent Phipps** Sue Wicker Bartolino Dr. Larry Chesley Marion and Janan Green Dr. Rhys Strasia David and Alicia Woodburn **In memory of Mary Slade** Kim and Thomas Wendt

**In memory of Juliette Sombaert** Russell Sombaert

**In memory of Robert J. Therrien** Paul Paslaski

**In memory of Molly Wagner** Karen and Steven Sisselman

**General contribution** J. Malcolm Beasley

# **Alzheimer's Disease Center Leadership**

The Boston University Alzheimer's Disease Center (BU ADC) is primarily supported through a grant from the National Institute on Aging. The BU ADC supports cutting-edge research and provides education and clinical care to individuals and families affected by Alzheimer's disease. Its leadership is listed below, alphabetically by Center Core.

Neil Kowall, MD, Center Director and Administrative Core Director Andrew Budson, MD, Center Associate Director Richard Fine, PhD, Pilot Grant Program Director Robert Green, MD, MPH, Center Associate Director Robert Stern, PhD, Clinical Core Director Christine Chaisson, MPH, Data Management & Statistics Core Director Angela Jefferson, PhD, Education & Information Transfer Core Director Ann McKee, MD, Neuropathology Core Director Alpaslan Dedeoglu, MD, PhD, Translational Animal Core Associate Director Lee Goldstein, MD, PhD, Translational Animal Core Director

The *BU ADC Bulletin* is published twice annually (**Dr. Angela Jefferson**, *Editor*; **Dr. Kathy Horvath**, *Co-Editor*; **Nicole Cantwell**, *Editorial Assistant*).

titor9-noN US Postage PAID Boston, MA Permit No. 1839



Boston University ALDC Bulletin

72 East Concord Street, B-7800, Boston, MA 02118