



# BU ADC Bulletin

Boston University Alzheimer's Disease Center

Spring / Summer 2002

## FROM THE DIRECTOR

*COLUMN BY NEIL KOWALL, MD*

As the Director of the Boston University Alzheimer's Disease Center (BU ADC), I am delighted to be able to contribute to our first newsletter! We see this biannual newsletter as a means of keeping in touch with our many valuable supporters: the research participants across many important ADC studies and other "friends of the Center." Our newsletter will have several features each issue. Our "Research Update" column will provide the latest news on several of our ongoing research studies, as well as information about new projects at the Center. The "Spotlight" column will report on a different topic related to Alzheimer's disease (AD) in each issue; in this edition, we focus on African Americans and AD. Finally, an "Alzheimer's in the News" column will summarize some recent news stories about AD that have attracted national media attention. We hope you will find the newsletter an educational and enjoyable read!

As you may know, the BU ADC is one of a select group of National Institutes of Health (NIH) funded centers focusing on research, education, and clinical care for Alzheimer's disease and other dementias. The Center features clinical, education, neuropathology, mouse breeding and administrative "cores." It is based jointly at the Boston University Medical Center and the Edith Nourse Rogers VA Hospital in Bedford, MA. Through clinical services and clinical research opportunities, the BU ADC addresses areas such as:

- 1) Memory changes in normal aging
- 2) Genetic and environmental risk factors for AD
- 3) Early diagnosis and treatment of people with memory disorders/prevention of AD
- 4) prevention of AD

The BU ADC recently received competitive funding from NIH to continue its work through at least 2006.

On behalf of ADC staff, I would like to thank all our supporters who have helped make this success possible! Together we can continue the growth of the Center as it works to provide many valuable services in the fight against Alzheimer's disease. ■

## RESEARCH UPDATE



Research nurse Deb Hanna with the ADAPT study's 100th participant. Read more about ADAPT in the "Research Update" section on Page 2

### HOPE

The Health Outreach Program for the Elderly (HOPE) is a research study that evaluates people with and without memory problems to increase our understanding of how memory and thinking change as people age. Its participants become part of a research "registry," which promotes other research related to Alzheimer's disease. The benefits of this research for those with the disease and their caregivers include: finding treatments, causes, methods of diagnosis, and better ways to provide care.

All HOPE participants are at least 55 years of age. The study takes place at two sites, Boston University Medical Center and the Bedford VA Medical Center. Participation involves a short physical examination and a test of memory and concentration. We ask that participants come with a study partner (either a close friend or relative), who is interviewed separately about the participant's memory. HOPE assessments take place on a yearly basis.

*Continued on Next Page*

<b>CONTENTS</b>	
<b>Research Update</b> .....	<b>2</b>
<b>New Studies</b> .....	<b>4</b>
<b>Spotlight: African Americans and AD</b> ....	<b>5</b>
<b>ADC Happening</b> .....	<b>6</b>
<b>Alzheimer's in the News</b> .....	<b>7</b>
<b>Contact Information</b> .....	<b>8</b>

# RESEARCH UPDATE *cont.*

## HOPE *cont.*

One important component of the HOPE study is our Brain Tissue Donation Program. All of our participants are asked to consider donating brain tissue after their death. Research using brain tissue can help scientists discover better treatments for AD.

In honor of its research participants, HOPE will be holding its first Participant and Study Partner Appreciation Luncheon on June 11.

For more information about HOPE please contact:

Lauren Kisver 617-638-8390  
Jeri Jewett 617-414-1189  
Eric Steinberg 617-638-5368

## Who's Who in HOPE

Neil Kowall, MD, *Director/Neurologist*  
Robert C. Green, MD, MPH, *Co-Investigator/Neurologist*  
Ladislav Volicer, MD, PhD, *Co-Investigator/Psychiatrist*  
Mark Moss, PhD, *Co-Investigator/Neuropsychologist*  
Sanford Auerbach, MD, *Co-Investigator/Neurologist*  
Charles Drebing, PhD, *Caregiver Coordinator/Psychologist*  
Nancy Emerson Lombardo, PhD, *Outreach Coordinator*  
Ann McKee, MD, *Neuropathology Coordinator*  
Alan Mandel, MD, *Neurologist*  
Patricia Boyle, PhD, *Neuropsychology Coordinator*  
Dawn Cisewski, PsyD, *Neuropsychology Fellow*  
Eric Steinberg, MSN, RN, CS, *Project Manager*  
Lauren Kisver, *Psychometrist/Brain Tissue Donation Coordinator*  
Jeri Jewett, *Participant Coordinator*

## ADAPT

The Alzheimer's Disease Anti-Inflammatory Prevention Trial (ADAPT) is a clinical research study funded by NIH to help determine if non-steroidal anti-inflammatory medications (NSAIDs) can prevent or delay the onset of AD.

It is the first-ever AD prevention trial using these medications. The BU ADC is one of six sites in this nationwide study of first-degree relatives (i.e., children and siblings) of people with AD. Our site recently enrolled its 200th participant and is well on its way to meeting its goal of 700 participants! 2,600 people will be enrolled study-wide, and participants will be followed for seven years. ADAPT will continue enrolling new participants through August, 2003.



ADAPT Site Director Dr. Robert C. Green and Project Manager Mary-Tara Roth with participants at the recent ADAPT Ambassador Program Luncheon.

## Adapt Ambassador Program

The Ambassador Program uses the ideas and talents of volunteers to assist ADAPT in reaching its recruitment goal of 700 participants. Ambassadors help recruitment by talking to family members or friends who might be interested in participating in the study, distributing ADAPT posters and flyers, and giving or arranging for presentations on the ADAPT project to community and/or professional groups.

On May 21, the ADAPT Ambassador Program was launched with a luncheon meeting held at BUMC. Twenty people attended, coming from the greater Boston area and as far away as Holbrook and Medway. A second group of volunteers will meet in Wakefield on June 4th to plan their activities.

Ambassadors are welcome to give whatever time they can spare. Training on ADAPT, promotional materials, and on-going support are provided to Ambassadors at no charge.

For more information about ADAPT or its Ambassador Program please contact Mary-Tara Roth at 617-638-5430. The national ADAPT website can be found at <http://www.2stopAD.org>.

## Who's Who in ADAPT

Robert C. Green, MD, MPH, *Site Director*  
Sanford Auerbach, MD, *Site Director*  
Mary-Tara Roth, RN, MSN, MPH, *Project Manager*  
Deb Hanna, RN, CS, *Study Nurse*  
Janet Nafissi, APRN, BC, *Study Nurse*  
Margaret Brickley, RN, MS, *Study Nurse*  
David Chrzanowski, *Psychometrist*  
Monique Nunez, *Participant Coordinator*  
Amanda Schmeihil, *Research Assistant*

# RESEARCH UPDATE *cont.*

---

## REVEAL

Risk Evaluation and Education for Alzheimer's Disease (REVEAL) is a National Institutes of Health funded research project based at the BU ADC. REVEAL is the first-ever randomized clinical trial to examine genetic-based risk assessment for adult children of people with AD. Information from this study will be used to determine if it is beneficial to educate people about their potential risk of developing AD sometime during their life.

REVEAL has completed its goal of recruiting more than 150 participants at three university medical centers: the BU ADC, Case Western Reserve University, and Cornell University. Preliminary findings from the study will be presented this summer at the 8th International Conference on Alzheimer's Disease in Stockholm, Sweden. An application to NIH was recently submitted for funding to continue and expand on the initial REVEAL project. If funded, "REVEAL II" will begin recruiting a new group of children and siblings of people with AD sometime next year.

For more information on REVEAL please contact Tamsen Brown at 617-638-5355.

### Who's Who in REVEAL

Robert C. Green, MD, MPH, *Project Director*  
Scott Roberts, PhD, *Co-Investigator*  
Adrienne Cupples, PhD, *Co-Investigator*  
Lindsay Farrer, PhD, *Co-Investigator*  
Tamsen Brown, MS, *Genetic Counselor Study Coordinator*

## MIRAGE

Multi-Institutional Research in Alzheimer's Genetic Epidemiology (MIRAGE) is a National Institutes of Health (NIH) funded research project based at Boston University School of Medicine. The goal of MIRAGE is to examine both genetic and non-genetic risk factors for AD. Funding was recently obtained from NIH to continue the MIRAGE project at its 12 sites in the United States, Canada, and Germany. Building upon the work that has been done during the last 11 years of this project, MIRAGE researchers will use neuroimaging data from magnetic resonance imaging (MRI) to evaluate the association between vascular risk factors and AD in

Caucasians, African Americans, and Japanese Americans. Information from the MIRAGE Study will speed the development of new diagnostic techniques and treatments for AD.

For more information about MIRAGE, please contact SanaYounis at 617-638-5040.

### Who's Who in MIRAGE

Lindsay Farrer, PhD, *Director*  
Robert C. Green, MD, MPH, *Associate Director*  
Sana Younis, *Project Manager*

## VIP

The VIP Study (Vulnerable Isolated Persons with AD) is a social intervention research project funded by the Alzheimer's Association to find effective ways to increase social support for isolated elders with Alzheimer's disease (AD). This study aims to improve the care and support received by adults who have AD, live alone, and do not have a central family caregiver coordinating their medical care. We are actively working to identify medical, psychosocial, and environmental factors that lead to the isolation of elders with AD and related dementias. Over the past year, three VIP papers were presented at the annual Gerontological Society of America conference. We anticipate that this study will continue for at least the next 18 months, and we will be enrolling new participants through May, 2003.

For more information about VIP, please contact Kevin Pertchik 781-956-2333  
Julie Patout 781-956-2318.

### Who's Who in VIP

Charles Drebing, PhD, *Principal Investigator*  
Nancy Emerson Lombardo, PhD, *Co-Investigator*  
Ann Hurley, D.Nsg., *Co-Investigator*  
Robert C. Green, MD, MPH, *Co-Investigator*  
Kevin Pertchik, PhD, *Research Associate*  
Julie Patout, MSW, *Research Associate*  
Tamara Harden, MS, *Research Associate* ■

# NEW STUDIES

---

## TIPS

The Treatment and Illness Perceptions Survey (TIPS) is a study funded by the National Institute on Aging to examine people's beliefs, knowledge, and intentions regarding AD and its emerging health care options (e.g., genetic testing).

The study assesses such perceptions among three groups:

- 1) Immediate blood relatives of people with AD
- 2) Current or former caregivers of people with AD
- 3) Adults age 50 and above without family history of the disease.

Findings from this study will be used to help design health education programs and related services for families affected by AD. The survey is conducted via a mailed questionnaire that takes about 30 minutes to complete.

For more information about the study, please contact Scott Roberts, PhD, at 617-414-1195.

## Treating Apathy in Alzheimer's Disease: A caregiver-Based Approach

Apathy, a syndrome of decreased motivation, is one of the most common behavioral problems reported in individuals with Alzheimer's disease (AD). Apathy is associated with functional declines among patients with AD and is a source of distress among their caregivers. The goals of this study, funded by the national Alzheimer's Association, are to determine:

- 1) whether a caregiver-based behavioral intervention can reduce apathy and thereby prolong independence in individuals with AD
- 2) whether the intervention can help reduce distress among caregivers. Sixty caregivers of people with AD will be recruited to participate in an 8-week behavioral intervention training program.

For more information about this study, please contact Patricia Boyle, PhD, at 617-638-5687.

## LEADS

The Lecithin Efficacy Alzheimer's Disease Study (LEADS) is a new study designed to investigate the acute effects of lecithin on the thinking abilities of people with early stage AD. Lecithin is a dietary supplement that may help the brain to increase its production of acetylcholine, thereby reducing the memory and other thinking problems seen in early AD.

The study is seeking 25 participants with early stage AD and will take place at the BU ADC and its Weymouth clinic. Participation in the study will last 8 weeks.

For more information about LEADS, please contact study coordinator Margaret Brickley, RN, MS, at 617-414-1191.

## PIP

The PIP study is a simulated AD prevention trial designed to examine new and potentially less costly methods for evaluating changes in memory and functional abilities in the elderly. Some clinic visits are involved, but many of the new instruments are self-administered and can be done at home. With the help of volunteers, this study may help us to develop new and improved AD research methods!

We are seeking individuals who are 75 years of age or older to participate in this 4 year study. Potential participants must also be able to identify a study partner (spouse, family member or friend) who is willing to attend study visits and fill out assessment questionnaires.

For more information about PIP, please contact Patricia Boyle, PhD at 617-638-5687.

## BEST

The Brain Enhancement Stimulation Treatment (BEST) is a study funded by the Ken Haas Memorial Trust to examine an innovative cognitive and memory enhancement program developed by Co-Principal Investigator Lynn L. Serper, Ed. D. Dr. Serper has used this program successfully with dozens of persons with brain injuries, including persons with Alzheimer's disease (AD). The program consists of creating a personalized, intellectually active environment, using structured cognitive activities and positive learning experiences to enhance thinking, social interactions, and self esteem. Eligible participants will

- 1) have a diagnosis of probable AD in its early stages
- 2) have a college education
- 3) commit to a weekly meeting with BEST staff, as well as to regular practice of program "mental exercises"
- 4) have a study partner

The aims of BEST are to refine, implement and scientifically evaluate this 6-month intervention for persons with early stage AD.

For more information about the study, please contact Principal Investigator Nancy Emerson Lombardo, PhD, at 781-687-2126 Or 978-621-1926 or by email: [nemersonlombardo@yahoo.com](mailto:nemersonlombardo@yahoo.com). ■

# SPOTLIGHT: AFRICAN AMERICANS AND AD

The topic of Alzheimer's disease in African Americans has been receiving increased attention in the medical community. For example, the national Alzheimer's Association has recently released a report entitled "African Americans and Alzheimer's Disease: The Silent Epidemic," available on internet at [http://www.alz.org/media/news/current/AA\\_ALZ.pdf](http://www.alz.org/media/news/current/AA_ALZ.pdf)

This report makes the following important points:

- 1) As a group, African Americans are hard hit by AD
- 2) The number of African Americans at risk for AD is growing rapidly
- 3) Genetic and environmental risk factors for AD seem different in African Americans than in other racial groups
- 4) Clinical practice and research studies are generally not designed to address the specific needs of African Americans with AD

The report calls for increased research on AD in African Americans, and the BU ADC is making several important efforts to heed this call.

For instance, Dr. Robert C. Green, Clinical Core director of the BU ADC, recently authored a paper that was published in the Journal of the American Medical Association. The article, based on data from the MIRAGE Study, described how children and siblings of African Americans with AD have a higher lifetime risk of dementia than do children and siblings of Whites with

AD. Other research at the BU ADC is also focused on issues regarding African Americans. The REVEAL project has added Howard University as a site in order to focus on special issues involved for African Americans in genetic risk assessment for AD. In addition, center investigators Dr. Rose Harvey, Dr. Nancy Emerson Lombardo, Dr. Scott Roberts and Dr. Dawn Cisewski have recently submitted separate grant applications to the National Center on Minority Health and Health Disparities and the national Alzheimer's Association, for funding to study issues of AD education, services, awareness, and screening among African Americans. Finally, we are continuing to recruit a greater number of African Americans for our ongoing studies, especially the HOPE project. Instrumental in such efforts are Nancy Emerson Lombardo, BU ADC Director of Community Outreach, Recruitment, and Retention, and Michael Kincade, an ADC affiliate who is the Multicultural Outreach Coordinator of the Alzheimer's Association's Massachusetts chapter. Mr. Kincade recently conducted an African American Community Forum in Dorchester, which focused on dementia care issues and was attended by 150 older community residents. Through such research and community partnership efforts, we hope to help address the growing needs of African American families affected by AD. ■



*MIRAGE co-investigators, staff and participants, with MIRAGE co-Principal Investigator, Dr. Robert C. Green at a participant appreciation luncheon last year at Morehouse School of Medicine in Atlanta, Georgia.*

# ADC HAPPENINGS

## Education Update



*BU ADC investigator Dr. Ladislav Volicer with staff from the Vermont Veterans Home displaying a poster presentation at the 9th Annual Caring for Persons with Alzheimer's Disease Conference*

## BU ADC Helps Sponsor Conference for Dementia Care Professionals

On March 27, well over 100 interdisciplinary caregivers attended the 9th Annual Caring for Persons with Alzheimer's Disease Conference, sponsored by the BUADC, the ENR Memorial Veterans Hospital, Northeastern University's School of Nursing and the Alzheimer's Association of Massachusetts. The conference was held at the National Heritage Museum in Lexington, MA, with the theme of "Integration of Care for Different Forms of Dementia." Featured presentations covered topics such as pain management and activity-focused care, with treatment issues examined from diverse perspectives, including neurology, psychiatry, nursing, social work, and occupational therapy. BU ADC investigators Dr. Neil Kowall and Dr. Ladislav Volicer were among the presenters, and ADC Education Core leader Dr. Rose Harvey was the primary organizer of the conference.

## BU ADC to Help Launch "SUPER IDEAR" Research Institute

The first annual summer research institute sponsored by the Bedford VA Medical Center Geriatric Research Education Clinical Center (GRECC), the BUADC, and the School of Nursing (Northeastern University) will be held at the National Heritage Museum in Lexington MA on June 6th and 7th. The institute is designed to promote research that will lead to improvements in treatment of pain, discomfort, agitation, and resistance to care in patients with dementia.

## Community Outreach



*BU ADC Director Dr. Neil Kowall with Bromley Heath Senior Center's volunteer coordinator Julie Martin and her granddaughter, at a recent meeting of the ADC's Community Advisory Council.*

## ADC Holds Community Advisory Council Meeting

As part of its efforts to work more closely with community organizations, the BU ADC Community Advisory Council (CAC) met on April 19th in Jamaica Plain. BU ADC staff met with representatives from organizations such as Bromley Heath Senior Center, the Multicultural Coalition on Aging, and the Boston Housing Authority to discuss how the ADC could improve its research, education, and clinical efforts. The lively discussion focused on community needs such as more accessible medical treatment and support services for African Americans with dementia; community-based memory screening; and lower-literacy education materials.

## African American Community Forum

BUADC members were on hand to support Michael Kincade, Outreach Coordinator of the Massachusetts Alzheimer's Association as he conducted the African America Community Forum for families, caregivers and people concerned about memory loss at the George Washington Carver Den in Dorchester on April 5th. 150 elderly community residents attended. Speakers included Reverend Raymond Hammond, Dr. Pamela Sheridan, Beth Israel/Deaconess Hospital and Dr. Jane Clutterbuck of the University of Massachusetts, Boston. Michael presided over an enthusiastic dialogue between community residents and local experts on AD.

## ADC Helps Celebrate 30th Anniversary of the Greater Boston Chinese Golden Age Center

On May 23, Nancy Emerson Lombardo of the BUADC hosted a celebration of the 30th Anniversary of the Greater Boston Chinese Golden Age Center. Golden Age Center founder Ruth Moy was honored by proclamations from Acting Governor Jane Swift, Boston Mayor Tom Menino and Speaker of the House Tom Finneran for the outstanding contributions the Golden Age Center has made to the elderly in the Chinese community. ■

# ALZHEIMER'S IN THE NEWS

---

## **Medicare to Expand Coverage of Services for Patients with Alzheimer's Disease**

On March 31, the New York Times reported that The White House has authorized Medicare coverage for the treatment of Alzheimer's disease. The policy change, initiated late last year, means that Medicare beneficiaries cannot be denied reimbursement for the costs of mental health services, hospice care or home healthcare solely because they have AD. The policy change was reportedly prompted by research demonstrating that people with AD, especially those in its earlier stages, can benefit from services such as psychotherapy and physical and occupational therapy.

## **Movie "Iris" Potrays Alzheimer's Disease on the Big Screen**

The recent major motion picture "Iris" (Miramax Films, 2001) provides what is perhaps Hollywood's most notable depiction of the effects of Alzheimer's disease. British actress Judi Dench was nominated for an Academy Award for her portrayal of Iris Murdoch, the acclaimed British novelist who died of the disease in 1999. The movie was based on "Elegy for Iris" and "Iris and Her Friends," two books by Murdoch's husband, John Bayley, that describe the couple's struggles with AD.

## **Journalist's Book on Alzheimer's Disease Receives Critical Acclaim**

The journalist David Shenk's latest work, "The Forgetting: Alzheimer's: Portrait of an Epidemic," (Doubleday, 2001) has been praised by critics as one of the best books available on the disease. The book traces the history of AD and includes informal case studies of such famous sufferers as Ronald Reagan and Ralph Waldo Emerson. One review states that this "engrossing book draws on an amazing array of scientific, historical, ethical, religious, mythological, literary, and artistic sources and is filled with fascinating characters and first-rate explanations of the science behind the disease." It was selected as one of Amazon's Best Books of 2001.

## **National Neurology Conference Includes Several Important Studies of AD**

The 54th Annual Meeting of the American Academy of Neurology was held April 13-20 2002 in Denver, Colorado and attracted almost 9000 attendees from the United States and around the world. There were nearly 200 scientific presentations that dealt with aging and dementia. An important theme of this year's conference was risk and protective factors for AD; several studies examined how certain factors (e.g., history of diabetes) might place people at risk for AD and related dementias, while other factors (e.g., higher education) might be protective.

The BU ADC was well represented at this year's conference. Dr. Robert C. Green and colleagues, using data from the MIRAGE study, evaluated the association between the use of statin medications and the risk of AD in over 2500 participants enrolled at 15 medical centers from the US, Canada and Germany. They found that the use of statins (medications usually used to lower cholesterol) for at least 6 months was associated with a significant reduction in the risk of developing AD. It is too early to tell whether statins should be used to try to prevent AD, but this study suggests an important need for future research in this area. The study received national attention, including reports in USA Today, the Wall Street Journal, and on NBC Nightly News.

## **BU ADC Investigator Leads Important VA Projects on Dementia Care**

BU ADC investigator Dr. Ladislav Volicer, a geriatric psychiatrist and Clinical Director of the Geriatric Research Education Clinical Center (GRECC) at the Bedford VA Medical Center, has helped spark two projects aimed at improving care for veterans with dementia. The first, the Alzheimer's Disease VA Consortium (ADVAC), is a project that promotes investigation of new and existing medications for veterans suffering from AD and related dementias by establishing collaboration between the VA's Cooperative Studies Program and pharmaceutical companies. Begun in 1999, ADVAC helps recruit investigators and provide logistic support and oversight of clinical trials, utilizing resources of the Cooperative Studies Program. Medications to be investigated will include not only those that enhance thinking abilities, but also those used for treatment of the psychiatric symptoms of dementia. To date, ADVAC has established relationships with 49 VA investigators, who have access to a combined population of over 6800 outpatients and 2200 inpatients. ADVAC has resulted in five funded clinical trials thus far and continues to look to help sponsor trials in both the private and public sectors.

Another important VA project is Advances in Home based primary care for End of life in Advancing Dementia (AHEAD II), a nationwide quality improvement initiative. This project reflects the fact that home based care is becoming an increasingly important part of the Veterans Health Administration's (VHA) health care system. The AHEAD II project is working with a variety of VHA outpatient clinic teams throughout the country to help improve end of life care for persons with dementia who choose to remain at home. 20 clinics were selected to participate in AHEAD II. In this 6-month project, each team is focusing on an area of care where they would like to make improvement, such as early intervention and symptom management, caregiver support and staff education. ■

### **Research Center Information:**

If you have general questions about the ADC, or specific questions or comments about this newsletter, please contact:

Catherine Pfau, M.M.H.S.

Clinical Projects Administrator, BU ADC

715 Albany Street, L-320

Boston, MA 02118

Tel: **(617) 638-5426**

Toll-free: **(888) 458-BUAD**

**[(888) 458-2823]**

Fax: **(617) 414-1197**

Email: **buad@bu.edu**

Website: **www.bualzresearch.org**

### **Clinic Information**

For diagnostic evaluation, management and treatment of memory-related problems, please contact either of the following BU ADC-affiliated memory assessment clinics:

#### ***Boston location:***

Geriatric Memory Assessment Clinic

Boston Medical Center

850 Harrison Avenue

Boston, MA 02118

Appointments: **(617) 414-4639**

#### ***South Shore location:***

Memory Assessment Clinic

Boston University Neurology Associates

1221 Main Street, Suite 401

Weymouth, MA 02190

Appointments: **(781) 331-9944**