

FALL 2006

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As a special education administrator in four different school districts over 25 years, George Scollins has spent much of his career educating and advocating for others. Today, despite a diagnosis of Alzheimer's disease (AD), Mr. Scollins continues his life's work through our feature article, *Approaches to Alzheimer's: Essay by George P. Scollins, Jr.* It is just one way that he and his wife Patricia are helping others who are coping with AD. Mr. Scollins was prompted to write the essay when he saw members of his support group struggling with their symptoms, but often reluctant to seek medical attention. Mr. Scollins urges others to see a physician for a diagnosis and to move on.

In their fight against AD, George and Patricia Scollins have participated in several research studies at the BU ADC. Mr. Scollins is determined that "whatever happens is going to be positive, not negative." We are honored to share excerpts of Mr. Scollins' essay in this issue of the Bulletin. For the full essay, please visit our website at www.bu.edu/alzresearch.

Approaches to Alzheimer's: Essay by George P. Scollins, Jr.

Twenty-one months ago I was diagnosed with AD. Since that time, I have learned a number of approaches that may help others. My major purpose in sharing this information is to communicate effective ways to face the realities of AD.

Approach #1: Do your best to make use of valuable time.

Avoid feeling sorry for yourself. Instead, focus on remaining positive and learning about participating in research studies, especially brain and dementia research studies. A song from the Second World War seems especially germane to a positive approach: *"Accentuate the positive, eliminate the negative, latch on to the affirmative, but don't mess with Mr. In-between. To illustrate my last remark, Jonah in the whale, Noah in the ark. What did they do when everything seemed so dark? They accentuated the*

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BU ADC Renewed Until 2011

Dr. Neil Kowall, BU ADC Director

I am delighted to announce that the Boston University Alzheimer's Disease Center (BU ADC) was recently awarded five more years of funding by the National Institute on Aging. Competition for this cycle of funding was especially strong. We owe our success to the exceptional talent of our ADC staff. Special thanks go to our Core leaders and our clinical teams that recruit and evaluate research participants. Our volunteers' willingness to be involved in research also has been key to our success. The BU ADC consistently ranks among the top Alzheimer's Disease Centers for participant involvement in research. We are known for our contributions to cutting-edge research by bringing together a wide range of investigators to study the diagnosis, treatment, and prevention of Alzheimer's disease and related disorders. The BU ADC has a relationship with the Alzheimer's Association which is recognized nationally as a model for ADC-Alzheimer's Association partnerships.

In the future the BU ADC will have an increased emphasis on research to better define normal aging and the transition to mild cognitive impairment and the earliest stages of dementia. We have increased our focus on mixed vascular dementia as demonstrated by new and ongoing collaborations with several large studies, including MIRAGE (Multi-Institutional Research on Alzheimer's Genetic)

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Raising over \$10,000 for the Alzheimer's Association, the BU ADC team had an impressive turnout for the Boston Area Memory Walk.

Alzheimer's in the News

The 10th International Conference on AD was held this past July in Madrid. The meeting, sponsored by the Alzheimer's Association, was the largest gathering of Alzheimer's researchers in history with more than 5000 attendees.

The BU ADC was well represented at the meeting, with more than 10 faculty and affiliates presenting research. HOPE Study Coordinator, **Eric Steinberg**, presented data examining factors associated with changing decisions for brain donation. Race is the most significant variable for predicting initial refusal for brain donation. Length of time in the HOPE Registry and a dementia diagnosis were associated with subsequent agreement after initial refusal. The REVEAL study's Principal Investigator, **Dr. Robert Green**, reported that AD genetic risk information can be safely delivered in a clinically feasible, "condensed" format. Co-Principal Investigator, **Dr. Scott Roberts**, reported that REVEAL participants age 60 and above fared as well as their younger counterparts in terms of anxiety and distress following genetic risk disclosure, but they were less likely to accurately recall their APOE genotype and lifetime risk information at 6 weeks following disclosure. **Dr. Benjamin Wolozin** reported that simvastatin is associated with a striking 75% reduction in the incidence of dementia in non-hypertensive participants age 65 years and older. No other statins showed a statistically significant reduction in the incidence of dementia. The large size of this dataset, including over 4.5 million subjects from the US Veterans Affairs database, provides strong support for the hypothesis that statins, and simvastatin in particular, might be beneficial in delaying the onset of dementia.

BU is a local site for the Flurizan study, and promising Flurizan study findings were presented in Madrid. Dr. Adrian Hobden, President of Myriad Pharmaceuticals, said "the results are consistent with a mode of action for Flurizan that is modifying the course of the underlying [Alzheimer's] disease process."

The next International Conference on AD will be held in Chicago in July 2008. More information can be found online at <http://www.alz.org/icad/>.



Presentations by BU ADC Investigators at the 10th International Conference on Alzheimer's Disease

Dr. Karen Cuenco, "Ethnic differences in MRI scans among AD patients and unaffected siblings in the MIRAGE study."

Dr. Robert Green, "Extended versus condensed protocol for disclosing genetic susceptibility for AD: The REVEAL study."

Dr. Nancy Emerson Lombardo, "Brain enhancement strengthening treatment: The Serper Method of Cognitive Rehabilitation to treat persons with AD; Final study results."

Dr. Angela Jefferson, "Decisional capacity for research participation in mild cognitive impairment."

Dr. Ann C. McKee, "Pathological evidence of dense Alzheimer lesions in the visual association cortex of cognitively intact elderly subjects."

Dr. Peter Morin, "FT-IR microspectroscopy: Analysis of AD and transgenic mouse amyloid deposition;" "Wnt-PCP signaling regulates cytoskeletal remodeling and neurite growth: effects on APP metabolism;" and "LRP6 Interacts with the retromer protein, vacuolar sorting protein 35."

Dr. Scott Roberts, "Age group differences in response to genetic risk assessment: Results from the REVEAL study."

Eric Steinberg, MSN, RN, CANP, "Factors associated with changing decisions for brain donation."

Dr. Benjamin Wolozin, "Associations between medication usage and the incidence of AD: Effects observed for cardiovascular and immunomodulatory medications."

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Epidemiology) and the Framingham Heart Study. The ADC will continue to make a special effort to research and address the needs of diverse populations.

Over the past 10 years we have made tremendous progress towards a better understanding of the cause of Alzheimer's disease. We now look forward to the application of this new knowledge to improved diagnosis and treatment for patients and families. With your help the BU ADC will continue to be at the cutting edge of new research and continue to make important contributions to fight Alzheimer's disease.

RESEARCH UPDATE

REVEAL Retreat

The Risk Evaluation and Education for Alzheimer's (REVEAL) Study is a multi-site study evaluating the psychological and behavioral impact of genetic risk disclosure on first-degree relatives of AD patients. On September 9th and 10th, the REVEAL Study held its annual retreat in Boston. Attendees included investigators and genetic counselors from three collaborating sites – Cornell, Case Western, and Howard University – as well as three new distinguished collaborators: Dr. Deepak Bhatt (Cleveland Clinic), Dr. Jason Karlawish (University of Pennsylvania), and Dr. Ronald Petersen (Mayo Clinic), whose research on mild cognitive impairment is internationally recognized.

Flurizan

The Flurizan Study closed enrollment on September 1st after successfully recruiting 1684 participants nationwide; the BU ADC was one of the top enrollment sites, with 40 participants. All participants completing the 18 month trial are eligible for the open label trial and will receive the study drug and follow up.

False Memory

Alzheimer's patients suffer from false memories - remembering things that never happened. In their study, "Episodic memory in Alzheimer's disease: Separating response bias from discrimination" (*Neuropsychologia* 2006 44:2222-2232), Dr. Andrewudson and colleagues examined patients' false memory tendency, by observing how often they responded, "Yes, I've seen that before," on a recognition memory test. Compared to healthy older adults, the patients showed worse memory and an abnormally liberal response bias (responding "yes" too liberally to test items). They concluded that as AD progresses, two distinct memory abnormalities develop: worse discrimination and a more liberal response bias.

APP and Klotho News

Dr. Carmela Abraham, Professor of Biochemistry, studies the normal biology of the Amyloid Precursor Protein (APP), the parent molecule for the amyloid beta peptide, a toxic protein implicated in AD. Recently, Dr. Abraham was awarded an Alzheimer's Association grant to study the "Significance of APP dimerization in Alzheimer's disease." Dr. Abraham also investigates changes that occur during normal aging of the brain. In this project, Klotho, an anti-aging gene, was found to be decreased as a function of age. Mice lacking Klotho develop changes seen in human aging such as cognitive decline, arteriosclerosis, osteoporosis, hair loss and infertility. In contrast, mice with higher than normal Klotho levels have an increased lifespan and are more resistant to disease. Dr. Abraham received an anonymous foundation grant to reveal Klotho's role in the young brain and find ways to increase its activity in the aging brain.

New Studies

CARE-Plus

The BU ADC is excited to announce CARE-Plus, a caregiver-based study which aims to reduce behavior problems in AD patients and improve caregiver's emotional well-being. CARE-Plus is a 5-week group intervention which offers 90-minute weekly sessions on AD, its symptoms, and tips for improving communication and interactions with the family member. It also focuses on family members' feelings about their own caregiving skills.

Flurizan II

The BU ADC has been selected to participate in the Global Flurizan study. This is a drug study which begins this fall for people with mild AD. Enrollment is limited. Please call 617-414-1078 for information.



(clockwise from bottom left) REVEAL Study Co-principal Investigator, Dr. Charmaine Royal; former REVEAL research assistant Dapo Akinleye, MPH; Dr. Robert Green, Principal Investigator; Dr. Scott Roberts, Co-Principal Investigator, and Dr. Robert Cook-Deegan, Chair of the External Affairs Board.

The ADC is pleased to announce the recipients of the 2006 Pilot Grant Awards:

Brandon Ally, PhD, Instructor of Neurology, Boston University School of Medicine, "Activation in the Posterior Association Cortex as a Therapeutic Marker."

Isabel Carreras, PhD, Instructor of Biochemistry, Boston University School of Medicine, "Relationship between Clusterin and Abeta Aggregation in a Mouse Model of AD."

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positive, eliminated the negative, latched on to the affirmative but did not mess with Mr. In-between."

Approach #2: Take care of important financial affairs.

Make use of services of an elder care attorney who is experienced in dementia-related issues. Establish a health care proxy, living will, and power of attorney so your wishes will be acted upon. The earlier you complete these items, the easier it will be for those you have delegated to carry out your wishes.

Approach #3: Keep your mind as alert and active as possible.

There are numerous ways to keep your mind active with regular activities, such as crossword puzzles and memorizing items. The AARP website (www.aarp.org) is among the better sources for these activities, such as "brain aerobics."

Approach #4: Stay healthy by exercise and proper diet.

Studies have shown that regular exercise, when combined with a healthy diet, is helpful in keeping your mind alert and able. Your doctor should be consulted if you plan to expand your physical activity level. Many health tips stress that what is good for your heart is good for your brain, including your ability to think and remember. Good sleeping habits help the body respond better to mental activities.

Approach #5: Volunteer to participate in Alzheimer's research.

Boston University and other medical schools are looking for volunteers to participate in studies. Even though participation may not improve your condition, it may help others now and in the future. Positive approaches certainly should take precedence to feeble or absence of effort to confront the realities of your situation.

Approach #6: Remain as active and social as possible.

Maintain contacts with old and new acquaintances. Outreach to others will greatly expand your horizons and outlook. Reaching out to others who have Alzheimer's may serve you well in viewing your own situation from a different perspective. It will assist others in becoming more positive under trying conditions.

Approach #7: Become as knowledgeable as possible of the status of Alzheimer's research.

Seek out this information and ask your healthcare professionals to interpret it for you. The amount of research in this area is staggering. One source of information is the Alzheimer's Association (www.alz.org). Meetings are regularly scheduled by local chapters, which are useful to keep abreast of developments. Periodic appointments with your neurologist are crucial in understanding your condition. The tests that accompany these visits provide ongoing assessment of where you are with the disease.

Approach #8: Recognize and accept that changes in your emotional and cognitive state are a reality of living with AD.

One major reality is recognizing that your care partner often has a clearer understanding of your emotional and cognitive status than you do. As a result, you are more aware of changes and their insights help you adjust in a positive manner.

Approach #9: Get help from support groups, family, and friends.

One of the most positive results of writing this essay has been a deeper understanding of myself and the positive responses I have had to the condition. I more deeply appreciate the help provided by my care partner and wife, Patricia, and the value of speaking at programs and to caregivers. As a result, my confidence in living with the condition in a positive manner has been expanded. My appreciation of the support group leaders and the contribution of the support group members are even more significant.

Approach #10: Accentuate the positive.

The most significant aspect of this experience is the way I changed over this period. I find myself crying at heart-rending television programs and movies. Newspaper articles or senseless violence produce a new but similar type of effect. My desire to help others is expanding as is my determination to remain positive despite the realities of Alzheimer's. However, the lyrics of a bygone song remain deeply embedded in my mind: *"You've got to accentuate the positive, eliminate the negative, latch on to the affirmative but don't mess with Mr. In-between."* Remain positive, it does make a difference!

Actively Recruiting Studies

Study Type	Study Title	Study Description
Memory & Cognition Studies	HOPE: Health Outreach Program for the Elderly	This longitudinal study increases our understanding of age-related changes in memory and thinking. It also serves as the Center's main research registry, where participants agree to be contacted regarding other ADC-approved studies.
	ADNI: Alzheimer's Disease Neuroimaging Initiative	This international study will determine if brain imaging (through MRI or PET scans), with the collection of blood and other biological specimens, can help predict the onset and monitor the progression of mild cognitive impairment and AD.
	Understanding False Memory in AD	This study seeks to better understand why patients with AD and other dementias frequently remember things that never happened. The ultimate goal of this NIA-sponsored study is to provide the basis for ways to reduce false memories in patients with dementia.
Caregiving Support & Education Studies	CARE-Plus <i>* new study</i>	A caregiver-based study whose aim is to determine whether an educational intervention can reduce behavior problems in patients with AD and improve caregivers' emotional well-being. The individual with AD is not involved in the study. CARE-Plus is a 5-week group intervention which offers 90-minute weekly sessions on AD, its symptoms, and tips for improving communication and interactions with the family member. It also focuses on family members' feelings about their own caregiving skills.
Genetic Studies	MIRAGE: Multi-Institutional Research in Alzheimer's Genetic Epidemiology	This longstanding study evaluates the association between genetic (hereditary) and non-genetic risk factors for AD. The study is currently recruiting people with a diagnosis of probable AD who also have an unaffected sibling who would be willing to participate with them. The study is being conducted at multiple sites in the US and abroad.
	REVEAL III: Risk Evaluation and Education for Alzheimer's Disease	This study is a multi-center, nationwide research project. The goal of REVEAL is to provide healthy adult children and siblings of AD patients with genetic susceptibility testing and information about their own chances to develop the disease.
Treatment Studies	Flurizan II™ <i>* new study</i>	The Flurizan II™ Study is a continuing multi-national, multi-center study that will evaluate the effectiveness of a new medication, Flurizan, in slowing the progression of AD. The study is looking for participants diagnosed with mild AD who have a caregiver who can accompany them to clinic visits.



Erin Whalen,
Recruitment
Coordinator for
BU ADC research
studies.

For more information, please call the recruitment coordinator, Erin Whalen, at 617-414-1078

ADC Happenings

Welcome

The BU ADC welcomes Dr. Hennie Lee, a post-doctoral research fellow who trained at the University of Amsterdam and was a resident neurologist in the Netherlands. Dr. Lee evaluates patients for Alzheimer's disease research studies.

A warm welcome to our new ADC Staff: David Essaff, MS, ADNI Study project coordinator; Judy Hibsichman, HOPE psychometrician; Susan Hiraki, MS, REVEAL Study genetic counselor and project manager; Carol Rossi, RN, clinical research manager; Michael Wake, MSW, MIRAGE Study project manager; Megan Wulff, ADAPT psychometrician.

We are also happy to work with the following new trainees: Kevin Blankevoort and Karin Volkers, from the Netherlands; Megan Campbell, Suffolk University doctoral student; Winston Chung, BU medical student; Dan Daneshvar, Lindsey Grace, and Meghan Lembeck, all students of the BU Graduate Medical Sciences Program; Megan Grace, Boston College student.

Congratulations

We are pleased to announce that Dr. Robert Stern has recently been named Co-Director of the Alzheimer's Disease Clinical & Research Program at Boston University.

Good-Byes

Many thanks to the following faculty and staff who have completed work at the BU ADC:

Scott Roberts, PhD, who served as Education Core Co-Director, Early Stage Project PI, and co-PI of the REVEAL study, is now an Assistant Professor at the University of Michigan; Danya Goodman, former HOPE psychometrician, is now a clinical psychology doctoral student; Jennifer Hunter, former research coordinator for the Driving Study is with the California Department of Public Health; Susan Lambe, former ADMIRE coordinator, is a doctoral student in clinical psychology; Erin Linnenbringer, genetic counselor and project manager for REVEAL, is a doctoral student at the University of Michigan; Sulaiman Sanni is completing studies at Boston College; Sarah Wong, an ADMIRE study research assistant, enrolled at the Tufts School of Medicine.

New Faculty

Dr. Anil Nair recently joined the ADC as an Assistant Professor of Neurology and as an attending neurologist at Boston Medical Center. Dr. Nair completed his medical training and general internal medicine residency at JIPMER, Pondicherry University, followed by a neurology residency at Temple University and the Cleveland Clinic. Dr. Nair



completed fellowship training in behavioral neurology at the Mayo Clinic under Dr. Ronald Peterson. A recipient of the National Talent Search Scholarship and Genesis Award in computational design, Dr. Nair's research interest includes mild cognitive impairment, AD, Lewy Body dementia, vascular dementia, and dementia patients' quality of life.

Dr. Nair will serve as an investigator for the HOPE and REVEAL studies and ongoing AD patient treatment trials, and see patients with memory disorders.

New Memory Clinics

A new Memory Diagnostic Clinic is starting at the Edith Nourse Rogers Memorial Veterans Hospital in Bedford by Drs. Maureen O'Connor and Andrew Budson. Neuropsychologists, neurologists, and nurse practitioners will perform evaluations and serve veterans with memory concerns. For information or to schedule appointments, contact Dr. O'Connor at 781-687-2830.

Dr. Robert Stern, Alzheimer's Disease Clinical and Research Program Co-Director and Director of Neuropsychology, is accepting referrals for neuropsychological evaluations at the Boston BU Medical Campus. Services include formal cognitive assessments and consultation for patients with known or suspected memory disorders as well as counseling and guidance to caregivers of persons with dementia. Cognitive assessments of driving safety-related skills will also be offered. To make a referral or schedule appointments, call 617-638-7100.

A Garden of HOPE

A “Garden of HOPE” was the theme for the HOPE Study’s Fourth Participant Appreciation Luncheon held on May 22nd at the Marriott Hotel in Newton, MA. Approximately 320 participants attended and were recognized for their valuable commitment to Alzheimer’s research.

The day began with introductions from HOPE Project Manager, Eric Steinberg, Center Director, Dr. Neil Kowall, Associate Director Dr. Robert Green, and greetings from the Alzheimer’s Association’s Massachusetts Chapter by Michael Kincade, Multicultural Outreach Coordinator. The program included an update on Alzheimer’s research which was presented by a distinguished panel of experts. Dr. Kowall provided an update on the latest research to detect, prevent, and treat Alzheimer’s disease; Dr. Andrew Budson spoke on memory systems in dementia; Dr. Robert Stern presented on

driving and dementia, and Dr. Ann McKee completed the panel presentations with a talk on the value of brain donation to Alzheimer’s research. The morning concluded with a lively question and answer session between the panel and audience.

Certificates of Distinction were awarded to all HOPE study participants with four or more years of commitment, and a standing ovation was given to the oldest participant in attendance, Ms. Diana Aharonian who celebrated her 104th birthday this year. Also, three raffles were held for prizes, including Barnes and Noble and Blockbuster Video gift certificates.

The BU ADC staff wishes to thank all who attended the luncheon. We appreciate your continued commitment to the BU ADC and the HOPE study.

Honorary and Memorial Contributions

The Alzheimer’s Disease Center welcomes honorary and memorial contributions. 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 Alzheimer’s disease.

In Memory of Henry Brown

Mrs. June Simeone

In Memory of Mary Teresa Boyd

Heidi and Marc Yacker

Connie and Debbie Britt

In Memory of Margaret Burzotta

Mr. and Mrs. Dominic Cardone

In Honor of Joan Cohen

Mr. and Mrs. Andrew Potash

In Memory of Rose Constantino

Ms. Nanette Cardone

Mr. and Mrs. Dominic Cardone

In Memory of sister of Adrianna DiGiusseppe

Thomas and Cathy Malian

In Memory of Irene Doulos

Thomas and Cathy Malian

In Memory of Margaret Foley

Mr. Charles R. Bickford

Miss Elizabeth Donovan

Ms. Irene Edmonds

In Memory of Jules Kopans

Jeff and Judy Fishman

In Memory of Rabbi Alvin Lieberman

Marilyn and Sol Sandperl

In Honor of Mary Snodgrass

Valerie J. Hanson

In Memory of Margaret Stolbach

Myrna and Carl Franzblau

In Memory of Pauline Conway

Louise Azevedo and Family

Margaret Fredricks and Family

Mary Lou Gale

Sue Morrissey and Family

Kathy Pereira and Family

Colleen Robichaud



10-year old Cassie Laslie presented a check for \$1700 to the BU ADC, which she raised in honor of her late grandfather who had AD.

The ADC would like to thank 10-year old Cassie Laslie, a student at the Gordon W. Mitchell Middle School in East Bridgewater, who recently raised \$1700 for our research center. Cassie raised the funds in honor of her grandfather, Julian Sarnicki, who was affected by Alzheimer’s disease. Cassie and her family also joined the BU ADC team for the annual Memory Walk, sponsored by the Alzheimer’s Association.

Research Center Contact Information

If you have general questions about ADC research, or specific questions or comments about this newsletter, or if you would like to make a donation to support the BU ADC, please contact:

Catherine Pfau, MMHS
Administrator Manager, BU ADC
715 Albany Street, B-7800
Boston, MA 02118
Telephone: 1-888-458-BUAD
Email: buad@bu.edu
Check out our website at www.bu.edu/alzresearch

Clinic Information

We provide expert diagnostic evaluation and treatment services for memory-related problems. Our clinical services are available at several locations:

In Boston's South End at BU Medical Campus:
Memory Assessment Clinic
Boston University Neurology Associates
Boston Medical Center
Doctor's Office Building, 7th Floor
Boston, MA 02118
Telephone: (617) 638-8456

*** New – Neuropsychological Evaluation Clinic**
Dr. Robert Stern
Boston University Medical Campus
Robinson Suite 7800
Boston, MA 02118
Telephone: (617) 638-7100

On the South Shore in Weymouth:
Memory Assessment Clinic
Boston University Neurology Associates
1221 Main Street, Suite 401
Weymouth, MA 02190
Telephone: (781) 331-9944

In Bedford (for veterans):
Edith Nourse Rogers Memorial Veterans Hospital
GRECC Unit
200 Springs Road
Bedford, MA 01730
Telephone: (781) 687-2701

*** New – Memory Diagnostic Clinic**
Edith Nourse Rogers Memorial Veterans Hospital
200 Springs Road
Bedford, MA 01730
Dr. Maureen O'Connor
Telephone: (781) 687-2830

BU ADC Bulletin

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