Delirium and dementia are conditions that can be confusing, both to experience and to distinguish. Both can cause memory loss, poor judgment, a decreased ability to communicate, and impaired functioning. In contrast to dementia, which is a chronic, progressive disease, delirium is a medical condition that manifests as sudden, severe confusion and rapid changes in brain function. Delirium is a medical emergency requiring prompt detection and treatment of the underlying cause. Individuals living with dementia are highly susceptible to delirium. Unfortunately, it can easily go unrecognized even by healthcare professionals because many symptoms are shared by delirium and dementia. Table 1 (page 4) compares and contrasts the cause and presentation of dementia and delirium.

Common causes of delirium include:
- Reaction to Medication(s)
- Fecal impaction
- Urinary retention
- Infection (urine, lungs, skin)
- Hypoxia (not enough oxygen getting to tissues as in congestive heart failure)
- Dehydration
- Low blood sugar/high blood sugar
- Pain
- Immobility
- Anemia
- Sensory problems—hearing and vision loss

Disclosure of Biomarker Results in Alzheimer’s Research Studies
By Melanie Shulman, MD, MPhil

NYU is one of 59 research centers in the US and Canada that participates in the Alzheimer’s Disease Neuroimaging Initiative (ADNI), a public-private partnership that was established in 2004 to carry out effective AD clinical trials and predict clinical outcomes by gathering extensive medical data, neuropsychometrics, and biomarkers (including blood, cerebrospinal fluid, and MRI/PET imaging) in hundreds of participants with normal cognition, mild cognitive impairment (MCI) and probable Alzheimer’s dementia. To date, ADNI has had a policy that researchers will not disclose research results to these participants. Similar “nondisclosure” policies have existed in other research fields, including cancer and genomics, until very recently.
A Letter from the Director

Thank you for your involvement in the NYU Alzheimer’s Disease Center (ADC). We are now in our twenty-fourth year of support by the National Institute on Aging. We continue to strive to advance current knowledge and understanding of brain aging and Alzheimer’s disease and work toward better treatment options and care for those living with memory impairment.

This year we’ve achieved many new milestones. We launched our new ADC website in January 2013, as www.NYULMC.org/adc, and now have over 100 Likes on our ADC facebook page, facebook.com/NYULangoneADC. In addition, our Education Core continues to disseminate research findings to both health care providers and the community at large. In the past year, we have successfully provided educational and training opportunities to 2,294 individuals. We conducted Memory Screening events for many older adults and have generated a number of substantial new ties to community organizations. We are particularly proud of conducting the first-ever conference fully in Spanish at NYU (September 26, 2012). This conference was attended by members of the Hispanic community including health care providers, patients and their caregivers.

Many concrete results have emerged from the work of our Clinical Core. These include improved treatments for Alzheimer’s disease (AD), improved understanding of AD onset and course, and improved knowledge of AD. Over the past year, the Multicultural Community Program has continued efforts to provide memory screenings and community education presentations on memory loss, dementia, and AD to participants in minority communities.

The Psychosocial Core continues to provide a comprehensive program of support, education, and resource information for all ADC participants and their family members from their first contact with the ADC through all stages of cognitive function, whether the participant lives at home or in a residential care facility. Family and ad hoc counseling are critical elements of our proven spouse-caregiver intervention. This Core also continues to support and provide data for research to develop and test psychosocial interventions. We are especially pleased with the success of Dr. Mittelman’s Chorus for people with dementia and their family members, as well as the feasibility study to begin to understand how to measure its benefits. To We are also delighted that the group recently had their 5th concert.

Our Neuroimaging Core continues to have a central role in developing improved image acquisitions for new research projects. The work of this core assures the development of MRI and PET imaging modalities for brain imaging. This is achieved by routine post mortem MRI imaging, correlated studies, customized MRI imaging, image analysis software development, and quality control of all studies. These activities significantly enhance the accuracy of AD diagnosis and contribute to identifying and testing the mechanisms of brain change in normal aging and dementia.

The Neuropathology Core continues to be an essential part of the ADC. It is critical to correlate the clinical diagnosis with the neuropathology. In addition, the Neuropathology Core provides an essential resource of tissue for research studies. This core’s expertise has been used for several very significant studies in the last year.

The Data Management and Statistics Core (Data Core) continues to perform data management and analysis for the all of our Cores, and for individual research projects affiliated with the ADC. This Core continues to provide secure data storage, maintenance, sharing and transmittals to National Alzheimer’s Coordinating Center (NACC). The Core continues to offer consultation and hands-on help in experimental data collection, design and statistical analysis to all collaborating investigators.

The Administrative Core continues to provide overall administrative supervision and coordination of the Center to optimize the scientific progress of affiliated investigators and ensure productive research. This core also offers and reviews our annual pilot study awards, which were awarded in March 2013.

Without the help of all our participants and staff, we would not be the successful ADC that we have become today. Thank you for all your efforts and dedication to enhancing the care of those affected by Alzheimer’s disease and related dementias.

Steven Ferris
Disclosure of Biomarker Results in Alzheimer’s Research Studies  
Continued from Cover

These policies are consistent with guidelines that separate research from clinical care that are based on strict criteria for the reliability of the research data as well as its clinical meaningfulness. The goals of these strict policies are to protect research participants from harm and to share only results with clinical utility.

In April 2012, the FDA approved the amyloid-imaging agent, florbetapir, as a tool to rule out—not diagnose—AD in cognitively impaired patients. FDA approval suggests that, for certain patients, amyloid-imaging has clinical value. Thus, investigators are now faced with a dilemma: should they tell participants clinically relevant research results, or adhere to the requirements of the research study that does not permit sharing of research data with participants or their clinicians? To address this question, we conducted an online survey of ADNI investigators to identify whether they disclosed biomarker results and, specifically, their attitudes about disclosure of amyloid-imaging results. We believed that surveying investigator and clinicians well-familiar with the strengths and limitations of AD biomarker data would help guide policies about returning research results to ADNI participants.

Highlights of the survey included the following: 1) the vast majority of ADNI investigators do not currently return amyloid imaging results of ADNI participants (~90% across all diagnostic groups.) 2) Despite knowing that nondisclosure of results is part of the ADNI protocol, participants frequently request biomarker results (~20% of ADNI investigators report requests from more than half of participants with normal cognition, and 22% report requests from more than half of participants with MCI.) 3) The majority of ADNI investigators would support the return of amyloid imaging results to all participants (including those with MCI or normal cognition) given FDA approval of florbetapir.

Overall, our findings from the survey suggest that the ADNI community favors a growing trend in biomedical research to revise its “no return” of results position. In free-form written responses to explain their points of view, the ADNI investigators provided many different rationales: from ethical principles (respect for ADNI participant preferences for information), to presence or absence of cognitive impairment, to technical issues related to biomarker reliability. One consistent theme expressed by the investigators was the need for more research on the process of disclosure itself—how best to provide the information, how to measure the effects of disclosure on participant well-being, and how to determine whether disclosure affects the collection of subsequent biomarker information. We plan to pursue these lines of investigation into disclosure of biomarker information here at NYU.

Ten percent of people over age 65, and half of those over age 85 develop memory and thinking problems. The most common cause of memory problems in older adults is Alzheimer’s disease, but there are other brain diseases that can cause dementia, including Lewy body disease, strokes, fronto-temporal disorders and normal pressure hydrocephalus (NPH). **Signs of memory loss include:**

- Gradual decline of memory
- Decreased ability to perform routine tasks
- Decline in clear thinking
- Problems with judgment and reasoning
- Confusion, gets lost easily
- Difficulty communicating with others
- Depression, anxiety, hallucinations
- Personality or behavioral changes
- Frequent falls or difficulty walking

The ADC offers a Counselor Hotline at 212-263-5728 for support and resource information.
### Table 1: Dementia versus Delirium

<table>
<thead>
<tr>
<th>Cause</th>
<th>Onset/Duration</th>
<th>Mental status testing</th>
<th>Alertness</th>
<th>Hallucinations and delusions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dementia</strong></td>
<td>Changes in memory and intellect are slowly evident over months or years.</td>
<td>Abilities don’t fluctuate in Alzheimer’s and most dementias with the exception of Lewy Body dementia.</td>
<td>Level of alertness not affected until late stages.</td>
<td>Not common; more likely to misperceive except in Lewy Body dementia wherein visual hallucinations are often present.</td>
</tr>
<tr>
<td>Alzheimer’s disease, Vascular dementia,</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Lewy body dementia, Fronto-temporal</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>dementia, or a related disorder.</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>Delirium</strong></td>
<td>Sudden confusion emerging over hours, days or weeks or sudden change from the person’s previous course of dementia.</td>
<td>Abilities fluctuate. Testing may vary from poor to good depending on time of day.</td>
<td>Alertness may vary from a “hyperalert” or easily startled state to drowsiness and lethargy.</td>
<td>Common and often of a frightening or paranoid nature</td>
</tr>
<tr>
<td>Triggered by medical illness, such as a</td>
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<td></td>
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<tr>
<td>urinary tract infection, pneumonia, and</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>dehydration.</td>
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<td></td>
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<tr>
<td>Acute phase of mental illness.</td>
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<td></td>
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<tr>
<td>Illicit drug use.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Withdrawal from drugs or alcohol.</td>
<td></td>
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<td></td>
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<tr>
<td>Medication interaction.</td>
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</tbody>
</table>

Delirium can be reversed. Early diagnosis and treatment offer the best chance of recovery.

**Dementia with Delirium**

Persons with delirium superimposed upon dementia experience a **sudden worsening** of their cognitive abilities as well as the classic signs of delirium: changes in levels of alertness, decreased attention, and fluctuation in abilities. Delirium increases a patient’s vulnerability to falling, oversedation, skin breakdown, immobility, aspiration pneumonia, and poor nutrition and hydration.

**Prevention of Delirium**

Measures to prevent delirium include **activities to avoid illness**: smoking cessation, a balanced diet and adequate fluid intake, regular exercise, avoidance of alcohol, and vaccinations to prevent influenza and pneumonia. Regularly **review medications** with the medical provider and avoid “offending” medications including antihistamines, benzodiazepine type sedatives, bladder relaxants, muscle relaxants, intestinal antispasmodics, centrally-acting blood pressure medicines (e.g., clonidine, methyldopa, anticholinergics), drugs with atropine-like effects, opioids (e.g., codeine, hydrocodone, morphine), and anti-nausea medication.
If delirium is suspected:
Those who are familiar with how the person normally appears are able to recognize when thinking or behavior changes abruptly. Thus they play a critical role in working with health care professionals in identifying delirium and developing a plan to help treat the underlying problem and prevent complications. Table 2 describes ways that family and friends can help the person with delirium.

Table 2 How family can help the person with delirium

<table>
<thead>
<tr>
<th>Communicate with medical provider and hospital staff.</th>
<th>Advocate to have needs met.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provide information even if not asked. Use words such as “this is not my mother.” Describe the person’s normal abilities to walk and take care of their needs as well as ability to follow direction and remember. Describe changes in behavior, abilities, and physical activity.</td>
<td>• Arrange with family and friends to stay with the person who is ill so that they can:</td>
</tr>
<tr>
<td>• Be prepared to list all medications.</td>
<td>• Encourage mobility including sitting in chair for meals and walking to the bathroom, and in the hallway when able.</td>
</tr>
<tr>
<td>• Report “clues” such as a change in eating, bowel, or bladder habits, swelling of ankles, difficulty breathing, signs of discomfort, pain or fever.</td>
<td>• Make sure the person is upright when eating and drinking to avoid aspiration (choking of fluid/food into lungs).</td>
</tr>
<tr>
<td>• Ask if the cause of the delirium has been determined.</td>
<td>• Offer fluids and nutrition; “finger foods” for example sandwiches may be easier to handle.</td>
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<tr>
<td></td>
<td>• Make sure hearing aid or glasses are worn if normally used.</td>
</tr>
<tr>
<td></td>
<td>• Ask that IVs and other tubes be removed as soon as possible. If IVs are needed, ask that that they are “camouflaged” rather than using restraints.</td>
</tr>
<tr>
<td></td>
<td>• To prevent injury, keep the bed as low as possible to the ground; ask about floor mats next to the bed.</td>
</tr>
</tbody>
</table>

During a hospitalization, the following interventions reduce the risk of delirium:
• use of sensory aids if needed: glasses and hearing aids
• early and frequent mobilization (sitting in the chair for meals and walking in the hall)
• avoiding sedatives and multiple new medications
• providing good nutrition and hydration
• controlling pain (for surgical pain, around the clock Tylenol often lessens the need for stronger medications)
• avoiding urinary catheters
• avoiding restraints
• regular assistance to the toilet
• normalizing the environment (e.g., pictures from home, familiar objects)
• cognitive stimulation: visits from family and friends and activities
Research Opportunities

**Longitudinal Study of Normal Aging, Mild Cognitive Impairment (MCI) and Alzheimer’s Disease**
Participants receive a comprehensive diagnostic evaluation and are re-evaluated every year. The goal is to improve early diagnosis and better understand the clinical course and causes of age-related cognitive decline and AD.
For information, call Dr. Thet Oo at 212-263-8088; thet.oo@nyumc.org

**Multicultural Community Dementia Screening**
The purpose of this study is to understand methods to best detect memory impairment in a multicultural community sample. Eligible participants include community-dwelling older adults aged 55 or above with and without memory complaints. Study participants will receive a comprehensive health screening, including pencil and paper testing of memory and thinking abilities.
For information, contact Licet Valois at 646-501-4213; licet.valois@nyumc.org

**Early Diagnosis and Imaging Studies**

**Bioanatomical Phenotype of Parkinson’s Disease With and Without Cognitive Impairment**
The purpose of this study is to understand methods to best detect and characterize memory impairment in older adults with Parkinson’s disease and understand the changes in the brain that cause memory problems. Older adults aged 60 or above with and without memory complaints will be recruited to receive a detailed clinical evaluation, pencil and paper testing of memory and thinking abilities, a magnetic resonance imaging (MRI) study of the brain and an electroencephalogram (EEG) to study brain activity.
For information, contact Crystal Quinn 646-501-4211; crystal.quinn@nyumc.org

**Biomarker Studies of Risk Factors for Cognitive Disorders in Older Adults**
The purpose of this study is to provide evidence-based methods to evaluate older adults for cognitive disorders and identify potentially modifiable risk factors, through the use of Positron Emission Tomography and Magnetic Resonance (PET/MR) scans. Eligible participants include older adults aged 40 or above without a pre-existing diagnosis of cognitive/memory deficit or with a diagnosis of Mild Cognitive Impairment due to Alzheimer’s Disease. Study participants will receive a comprehensive health screening, including pencil and paper testing of memory and thinking abilities and a PETMR scan of the brain. Participation is compensated.
For information, contact Crystal Quinn 646-501-4211; crystal.quinn@nyumc.org

**Clinical Correlates of Longitudinal PET Changes in Alzheimer’s Disease**
The goal is to assess combining FDG-PET imaging (brain metabolism) with cerebrospinal fluid (CSF) biomarkers and PET amyloid imaging (using a tracer that binds to brain amyloid) in predicting cognitive decline. We are enrolling mild AD, MCI and normal subjects over age 20, who receive a comprehensive evaluation: neurological/physical exam, MRI and PET, memory testing, laboratory blood-work, EKG and lumbar puncture. Participants receive results and are compensated for their time and effort.
For information, contact John Murray at 212-263-7795; john.murray@nyumc.org

**Imaging Neuroinflammation in Alzheimer’s Disease with [11C] Arachidonic Acid (AA) and PET**
The goal is to validate a new inflammation PET imaging agent known as [11C] Arachidonic Acid (AA) in individuals with and without cognitive dysfunction. Inflammation is a key component of the pathological processes (amyloid beta plaque deposition, neurofibrillary tangles, neuronal loss, astrocytosis) that are found in patients with Alzheimer’s disease (AD). An in vivo neuroimaging method to measure markers of neuroinflammation would represent a major advance in the understanding of the pathophysiology of AD and other dementing disorders. We are enrolling normal and dementia subjects over the age of 65 who will receive physical examinations, blood tests, neuropsychological evaluation, EKG, MRI; [11C]PIB, [18F]FDG, and [11C]AA PET scans. Participants are compensated for their time and effort.
For information, contact Ricardo Osorio at 212-263-3258; ricardo.osorio@nyumc.org

**MRI Progression Markers of Cognitive Decline in the Elderly**
This project investigates the relationship between plasma amyloid beta protein levels and brain vascular response to CO2 (measured with MRI). Additional tests include brain structure measurement and CSF tau levels.
Participants should have mild cognitive impairment (MCI), and will receive a comprehensive evaluation consisting of a neurological/physical examination, neuroimaging (MRI and ASL), memory testing, laboratory blood-work, ECG and lumbar puncture. Participants receive results and are compensated for their time and effort. For information, contact Nicole Spector at 212-263-7563; nicole.spector@nyumc.org

Biomarkers in Early Alzheimer’s Disease
This project builds upon our new work, demonstrating the value of cerebrospinal fluid (CSF) and blood biomarkers. We combined these analyses with novel MRI technology which looks at cerebral blood flow, a possible mechanism-based marker for early Alzheimer’s disease. We are enrolling normal subjects over the age of age 50, with and without mild memory complaints, to receive a comprehensive evaluation: neurological/physical exam, MRI and memory testing, laboratory blood-work, EKG and lumbar puncture. Participants are compensated for their time and effort.

Are sleep disturbances a risk factor for Alzheimer’s disease?
Sleep is a complex behavioral state involved in brain restoration, body rhythms, and memory consolidation. The term sleep-disordered breathing (SDB) is commonly used to describe the full range of breathing problems during sleep in which not enough air reaches the lungs (hypopnea and apnea). Advancing age is accompanied by physiological changes in respiratory functions during sleep, resulting in a prevalence of SDB of 30-80% in individuals aged ≥60 years, compared to less than 10% in people aged 40. In the elderly, SDB is for the most part asymptomatic and less dependent to obesity, snoring, and sleepiness than SDB at a younger age. No study has addressed appropriately the neurological impact of SDB in the elderly. Our plan is to use home-based monitoring of SDB to identify a sample of normal elderly subjects with SDB. All subjects will receive plasma measures of inflammation, clinical, neuropsychological, and neuroimaging (PIB and MRI) studies. Some participants will be invited to perform an in-lab sleep study (at the hospital). This novel study will provide additional evidence for the link between sleep respiratory changes in the elderly and Alzheimer’s disease (AD). Given the high prevalence of both SDB and AD, identifying a potential mechanistic association would be of the highest relevance in establishing new pathways for AD treatment.

Blood pressure, cerebral perfusion and cognitive performance in hypertension
Hypertension (a chronically high blood pressure) may lead to impaired blood delivery to the brain, and consequently can cause brain shrinkage and cognitive decline. NYU Center for Brain Health invites adults age 65-80, with or without hypertension (treated with only one anti-hypertensive medication), to participate in a research study. The purpose of this study is to examine the effects of one’s current blood pressure on their brain, memory and thinking in the future. Your visit includes clinical medical exams, neuropsychological exams, blood work, ECG, carotid ultrasound, brain MRI, and 24-hour ambulatory blood pressure monitoring.

All clinical trials require participants to have a study partner, a friend or relative who can accompany volunteers to clinic visits. The person should have regular contact with the volunteer and will be able to attend all study visits. For information about any of the studies listed below, please contact Dana Pogorelec at 212-263-5708; dana.pogorelec@nyumc.org, Brittany Cerbone at 212-263-5845; brittany.cerbone@nyumc.org or Christina Michel at 212-263-0771; christina.michel@nyumc.org

Alzheimer’s Disease Neuroimaging Initiative 2 (ADNI2)
We are seeking healthy volunteers who are concerned about their memory, as well as volunteers who have mild Alzheimer’s disease, to participate in ADNI, a landmark NIH research study examining the subtle changes in the brains of older people many years before symptoms of memory decline. The main goal is to identify and understand which biomarkers best track the progression of memory/cognitive decline. Volunteers may be fluent in English or Spanish and must be either 65+ years of age and be in good general health with slight memory concerns, or have diagnosed mild Alzheimer’s disease and be 65+ years of age. This is not a drug study. Using advanced imaging techniques and biomarkers found in blood and cerebrospinal fluid, we will monitor your health and memory over five years - at no cost to you.

Clinical Trials Opportunities continue on next page
**BACE (β-secretase) Inhibitor as Treatment for Mild-Moderate Alzheimer’s Disease**
The purpose of this Phase 2/3 study is to determine whether an oral, investigational medication will affect cognitive and behavioral functioning in individuals with mild to moderate Alzheimer’s disease. The BACE inhibitor works by blocking the one of ways that beta amyloid, a protein linked to the cognitive and behavioral problems associated with Alzheimer’s disease, is produced in the brain. There is hope that this drug will reduce amyloid plaque build-up in the brain, thus improving the negative symptoms and slowing the overall progression of the disease. We are currently enrolling individuals with mild-moderate Alzheimer’s disease who are 55-85 years of age. If you choose to participate you will receive comprehensive medical follow-up including a neurological/physical exam, memory testing, laboratory blood-work, an EKG and a MRI scan.

**MAO-B Inhibitor as Treatment for Moderate Alzheimer’s Disease**
This Phase 2 trial will study the safety and efficacy of an oral medication for those with moderate Alzheimer’s disease, who are currently taking either donepezil (Aricept), rivastigmine (Exelon), or galantamine (Razadyne) as the primary Alzheimer’s disease medication. Research shows that MAO-B levels are increased in those who have AD, something that can lead to various problems, including brain cell death. This drug is a MAO-B inhibitor, which means that it prevents the enzyme MAO-B from over-functioning. By decreasing MOA-B levels in the brain, it is hoped that this drug will improve some of the negative effects of Alzheimer’s disease. We are currently enrolling individuals with moderate Alzheimer’s disease who are 60-90 years of age. If you choose to participate you will receive comprehensive medical follow-up including a neurological/physical exam, memory testing, laboratory blood-work, an EKG and a MRI scan.

**Transcranial Magnetic Stimulation (TMS) and Cognitive Training for Mild to Moderate Alzheimer’s Disease**
This trial will involve a non-invasive procedure that uses a magnetic field to stimulate activity within the brain. Researchers believe that through repetitive treatments, TMS in combination with cognitive training may improve the cognitive (memory and thinking) abilities of patients with mild to moderate Alzheimer’s disease (AD). TMS has been successfully used in studies for psychiatric and neurological conditions including depression, mania, obsessive-compulsive disorder, post traumatic stress disorder, schizophrenia, and Parkinson’s disease. For information, contact Dana Pogorelec at 212-263-5708; dana.pogorelec@nyumc.org, Christina Michel at 212-263-0771; christina.michel@nyumc.org, or Brittany Cerbone at 212-263-5845; brittany.cerbone@nyumc.org

**Alzheimer’s Disease Prevention Study**
Are you currently in good physical and mental health but concerned that your memory is not as good as it used to be? We are exploring the use of currently FDA approved medications that may help safeguard the memory region of the brain known as the hippocampus by promoting the growth of neurons. If you are between the ages of 60 and 80, in good general health, and worry about changes in your memory, you may be eligible for this study.

**Clinical Trials at the Nathan Kline Institute in Rockland County**
For information on any of the studies listed below, please contact Dr. Antero Sarreal at 1-800-521-8367, 845-398-6532 or 845-398-5582; asarreal@nki.rfmh.org

**Phase II Multicenter, Randomized, Double-Blind, Placebo Controlled, Parallel-Group two year study to Evaluate the effect of subcutaneous RO4909832 on cognition and Function in Prodromal Alzheimer’s Disease.**
This study will evaluate the effect of Abeta amyloid lowering monoclonal antibody (gantenerumab) versus placebo. Accumulation of a particular protein, beta amyloid, is thought to be related to the progression of Alzheimer’s disease (AD) and begins well before the onset of AD dementia and probably even before any cognitive decline associated with AD. It is therefore reasonable to think that the benefit of anti-amyloid therapy (gantenerumab) may be greater if initiated before prominent symptoms of AD manifest, such as dementia. This study is enrolling subjects who do not yet meet a diagnosis for Alzheimer’s dementia, but have findings that characterize the predementia or prodromal phase of AD and are between 50-80 (inclusive) years of age. The subjects must score between a 24-30 on the Folstein (MMSE).

**Alzheimer’s Disease Neuroimaging initiative-2 (ADNI)**
The overall goal of this project is to determine the relationships among clinical, imaging, genetic, and biochemical biomarker characteristics of the entire spectrum of Alzheimer’s Disease (AD), as the pathology evolves from normal aging through very mild symptoms, to mild cognitive impairment (MCI), to dementia. This study is enrolling subjects who currently have a diagnosis of Alzheimer’s disease (AD) or subjects who do not have a diagnosis of AD, but have significant subjective memory concerns (SMC) and be between 55-90 (inclusive) years of age. Subjects with AD must have a score between 20-26 on the Folstein (MMSE) and subjects with SMC must score between 24-30 pm the Folstein (MMSE).
A Phase 2, randomized, double-dummy, double-blind, placebo-controlled study to assess the efficacy, safety and tolerability of AVP-923 (dextromethorphan/quinidine) for the treatment of symptoms of agitation in patients with Alzheimer’s disease.

This study is evaluating the efficacy, safety and tolerability of AVP-923 (dextromethorphan/quinidine) for the treatment of symptoms of agitation in patients with Alzheimer’s disease. AVP-923 has not been approved for the treatment of agitation symptoms associated with Alzheimer’s disease by the U.S. Food and Drug Administration (FDA). Alzheimer’s disease is a disease of the brain that destroys brain cells and causes problems with memory, thinking and behavior. Agitated behaviors such as irritability and restlessness, physical and verbal aggression, and pacing and wandering are major problems, can be difficult to manage, and can impact your quality of life.

**Other Studies and Support Programs**

**Early Stage Support Group**
The center offers facilitated support group meetings to people in the early stages of AD. Studies suggest these groups may alleviate depression and social isolation, enhance coping skills, improve self esteem and provide education and mental stimulation in a safe environment. Currently, these groups are being held on Thursday’s (12pm-1:30pm) and Fridays (2pm-3:30pm).

For information, contact Ursula Auclair at 212-263-2245; ursula.auclair@nyumc.org

**Support for Caregivers**
A peer facilitated support group for caregivers conveniently meets at the same time as the early stage AD support group held on Thursday’s from 12 to 1:30pm. In addition, a caregiver group meets on Mondays from 10am to 11:30am.

For information, contact Ursula Auclair, LCSW at 212-263-2245; ursula.auclair@nyumc.org, or Ronit Notkin, LMSW at 212-263-2047; ronit.notkin@nyumc.org

**The Multicultural Program**
The Multicultural Aging and Memory Assessment program provides free educational presentations and memory screenings at various community organizations and centers for health care providers, patients, family members, and others who may be interested in learning more about normal aging, memory problems, dementia, and Alzheimer’s disease. The program is committed to providing memory assessment and clinical trials research opportunities to an ethnically and socioeconomically-diverse patient population.

For information, contact Dorothy Patterson at 212-263-3201; dorothy.patterson@nyumc.org or Milena Perez at 212-263-7651; milena.perez@nyumc.org (Spanish)

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**Brain Donation Program**

The NYU ADC is grateful to donors and their families for participation in our Brain Donation Program. Brain autopsy provides a definitive diagnosis for families while contributing to important research on the causes and treatment of brain aging and AD. Donors with and without memory impairment are eligible. For more information on the Brain Donation program, call Lynne Leung at 212-263-5108; lynne.leung@nyumc.org

Please see page 11 for Frequently Asked Questions

Please visit our website at nyulmc.org/adc and like us on facebook at facebook.com/NYULangoneADC
Expanding service usage of individuals with early stage Alzheimer’s Disease: Project Learn MORE By Magda Tolea, PhD

Provision of support services and its impact on the lives of dementia patients and their family caregivers have been the focus of research for many years. Many of the 44 million informal caregivers currently caring for older individuals with cognitive impairment do not feel prepared for their caregiver role and do not know how to find and access available resources to help them better care for their affected family members. With the aging of our population and the expected increase in the number of Americans with Alzheimer’s Disease, finding ways to help these members of our society lead meaningful and healthy lives in their own homes is of paramount importance.

Although support received at any stage of dementia may be beneficial, support provided as early as possible in the disease process can offer superior health and other benefits especially when the diagnosed person is included in these efforts. ‘The period of early stage diagnosis represents a critical time when both caregivers and care-receivers can come to terms with the diagnosis and make plans for how they will arrange future care” (Whitlatch, 2006).

To help efforts of identifying dementia in the community and increasing usage of available services, NYU researchers at the Pearl I. Barlow Center for Memory Evaluation and Treatment partnered with the Missouri Department of Health and Senior Services and the local Alzheimer’s Association (AA) Chapters and Area Agencies on Aging (AAA) to implement and evaluate Project Learn MORE (Missouri Outreach and Referral Expanded; PLM) - a program designed to identify individuals with early stage AD in the community and connect them with appropriate resources. By strengthening partnerships between the principal players in the dementia care, the main goal of PLM was to provide a coordinated method to identify and guide those experiencing cognitive impairment who have not sought medical evaluation and/or are not fully utilizing supportive services and provide them with tools to increase their ability to cope with the disease.

As part of the program, the participating AAAs incorporated AD8 – a brief dementia screening tool in their client care coordination system. Of the 3,682 AAA clients assessed, 344 showed evidence of early cognitive impairment (i.e. AD8 of ≥2) and were referred along with their families to AA Chapters to receive supportive services and an intervention to increase coping skills. Of these, 244 clients received the intervention, which consisted of an individualized care consultation with the care-receiver, the caregiver, or both in which specific needs were assessed. Based on the identified needs, clients received personalized care plans that addressed emotional, educational, future care planning, and financial needs along with referral to needed supportive services. Clients were followed-up bi-monthly for a 2-year period.

To evaluate the intervention, researchers asked clients and their caregivers a series of questions about their knowledge about AD, confidence in dealing with the disease, disease-associated burden, functionality, and mood before and after they received the intervention. After the intervention, care-receivers were more confident in their knowledge about AD and reported improved mood compared to their before-the intervention levels. Among caregivers, PLM improved confidence about disease knowledge as well as about their ability to find resources to better care for the affected person and for their own health. However, PLM also increased caregiver burden and stress. PLM was also associated with a 13-fold increase in the probability of delaying death and with a 3-fold increase in delaying transitions to care from home to a nursing home or assisted living facility and provided other benefits such as significant risk reduction when compared to ‘usual services’ offered by AA. These health benefits compared favorably against previous similar interventions. Moreover, the AD8 dementia screening tool was embraced by the vast majority of AAA caseworkers who reported high rates of satisfaction.
with its administration and effectiveness in identifying memory loss. Also, at the conclusion of the intervention most care-receivers and caregivers reported being satisfied with PLM and its impact on their lives, although caregivers appeared to benefit more from the program in terms of overall satisfaction, decreased fear and distress related to the new diagnosis, and improved confidence and coping skills to handle their caregiver role.

Taken together these findings suggest that psychosocial and educational interventions that enlist multiple public and private dementia care and advocacy entities can offer health benefits to both the affected individuals and their caregivers. By decreasing depression among care-receivers and increasing confidence in both care-receivers and caregivers, interventions such as PLM can lead to improved quality of life of all those affected, an important public health goal. The slight increase in caregiver burden and stress following the intervention can be attributed to the recently established AD diagnosis, the heightened awareness of family members of their new role as a caregiver of a person, and the better understanding of the different stages of AD and its consequences on their loved ones. Increased and longer durations of follow-up would likely provide the tangible, informational, and emotional social support to reduce and/or limit this initial increase in perceptions of burden and stress. The study also demonstrated that new cases of dementia can be readily detected in the community and that community-based interventions such as care consultations offered by the Alzheimer Association could have significant impact in reducing resource utilization, delaying nursing home placement and decreasing Medicaid-related costs while improving patient- and caregiver-centered outcomes.

Whitlatch CJ, Judge K, Zarit SH & Femia EE. Dyadic intervention for family caregivers and care receivers in early stage dementia. Gerontologist, 2006; 46:688-694

Brain Donation: Frequently Asked Questions

Q: **What will my Healthcare Proxy/family have to do?**
A: At the time of death, the program coordinator must be contacted. At this time we will work together to initiate the procedure.

**Consent** – If we do not have the donor’s consent on file or available at the time of the call, a request will be made to have the donor’s healthcare proxy/family member sign a consent form. The consent form will either be faxed or e-mailed to the consenting party.

To help avoid possible problems or questions that may be encountered at such an emotional time, it is recommended that preliminary arrangements be coordinated in advance whenever possible. We advise you to speak with your healthcare proxy/family about your interest in this program, request additional information from us for them if they require it and always feel free to call with any questions or concerns.

Q: **Can family members also become brain donors?**
A: Yes! As a relative of an individual with Alzheimer’s disease, your brain tissue is very important for comparative studies. Ideally, your family member should have an evaluation done at the NYU ADRC also.

Q: **What if I change my mind and no longer wish to donate?**
A: If you change your mind about participation in our Brain Donation Program, simply let the coordinator know and your name will be removed from the database.

Q: **Will the results of the examination be available?**
A: Yes, the family is provided with a copy of the final neuropathology report (provided about 6 months after procedure is performed) and are invited to come to speak with our neuropathologist to address any questions and concerns generated from the information provided.

Q: **How does this work?**
A: The NYU Brain Donation Coordinator can facilitate this by identifying a qualified facility near your new home that can do the procedure.

Q: **Can I still participate even if I move out of New York?**
A: Participation in this program does not have to change if you move from or live out of the New York area. Arrangements can be made to have the brain donation procedure done in a hospital or facility close to where you have relocated.
We continue to welcome your participation in Center activities and research programs. Federal support for medical research has been reduced in recent years. Thus, we increasingly depend on the generosity of our Participants to help strengthen and expand our research and clinical programs, and greatly appreciate your financial support. Thank you.

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- Thet Oo
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- Isabel Monteiro
- Carol Torossian
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**Research Neuropsychologist**
- research@nyumc.org, put “e-connect” in the subject line!