The Social Worker Role in the Research Center
by Licet Valois, LMSW, MPS

Once a participant has been diagnosed with dementia during a research study, the participant and their study partner may experience different needs and concerns. Some people need assistance accessing services or government benefits like home care services, food stamps, or applying for Medicaid; some need supportive counseling to better cope with a new diagnosis, while others might not need any help at all.

In a Research Center, a variety of professionals are involved with many aspects of the study. A social worker is often one of the clinicians available to help the participant and the study partner manage some of the concerns related to the diagnosis received.

At the NYU Alzheimer’s Disease Center, we utilize a comprehensive approach. A team of knowledgeable clinicians work together to offer support to the participant and study partner and to collect research data.

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Sleep and Aging
by Ricardo Osorio, M.D.

Sleep is a complex state involved in memory consolidation, brain restoration, and regulation of the immune and cardiovascular systems. Normal aging is characterized by a diminished quality of sleep with: decreased total sleep duration, sleep fragmentation, shallower sleep, increase in daytime napping, and a tendency to go and arise from bed earlier than younger adults.

In addition, elderly individuals experience a higher prevalence of medical conditions that make sleep difficult such as cardiac, neurological and pulmonary disease, or any condition associated with chronic discomfort and pain, like arthritis. Advancing age is also accompanied by physiological changes in respiratory functions during sleep, resulting in an increase of snoring, increased airway resistance and obstructive sleep apnea. The term sleep-disordered breathing (SDB) is commonly used to describe this full range of breathing problems during sleep. SDB is common, with a prevalence of 30-80% in individuals aged 60 years or older, compared to less than 10% in people aged 40. “Late-life” SDB is for the most part asymptomatic and less dependent to obesity than sleep apnea at a younger age.

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Your continued involvement in the NYU Alzheimer’s Disease Center (ADC) is extremely valuable and contributes directly to our efforts to better understand, treat and eventually prevent Alzheimer’s disease (AD). We are now in our twenty-fourth year of support by the National Institute on Aging (NIA) as one of thirty ADCs across the United States. Our mission is to provide critical core resources that facilitate the important work of scientists who are studying normal brain aging and the nature, causes, early diagnosis, treatment and prevention of Alzheimer’s disease (AD) and related disorders. Here is a brief summary of the ADC activities you may participate in:

The Clinical Core provides well-diagnosed research participants (healthy normal older adults and individuals with mild cognitive impairment and AD) who receive comprehensive annual research evaluations. The Clinical Core also collects and stores biological material, such as blood and cerebrospinal fluid (CSF) samples, for use by researchers studying early diagnosis and disease mechanisms. Participants also enroll in the Brain Donation Program of the Neuropathology Core, which provides brain tissue essential for laboratory research and for confirmation of changes observed clinically. The Data and Statistics Core stores and maintains the Center’s comprehensive clinical data, and assists researchers with data management and statistical analyses. The Education Core facilitates coordination and recruitment and retention of new participants, helps train new scientists and educates health care providers and the public about the results of our research on aging and AD. The NYU-ADC is unique as one of the only Centers with two additional core facilities: A Neuroimaging Core which focuses on brain imaging, providing researchers with cutting edge data from MRI and PET scans that support pioneering research on the early brain changes associated with cognitive decline; and a Psychosocial Core which assesses the psychological and emotional consequences of caring for a relative with dementia and provides resources for the study of psychosocial interventions for patients and family members to reduce the impact of AD.

In addition to gaining a better understanding of the causes and improving the treatment of AD, the pioneering research affiliated with the ADC focuses on early diagnosis, early treatment and prevention. NYU scientists previously contributed to the understanding of mild cognitive impairment, which is now recognized as a very mild “prodromal” clinical stage of AD. A major current research focus is on the transition from “normal” brain aging to the earliest pathology caused by AD, and on the development and testing of tests and treatments that may eventually lead to AD prevention. This research requires the participation of older adults willing to contribute their time so that future generations will not suffer from AD. Success in this important endeavor depends on the critical partnership between the ADC and our valuable participants.

About the NYU Alzheimer’s Disease Center
The National Institute on Aging funds Alzheimer’s Disease Centers (ADCs) at major medical institutions across the United States. We strive to improve diagnosis and care for people with Alzheimer’s disease (AD), while at the same time focusing on the long-term goal of finding a way to cure and prevent AD. Our Center provides many services, including:

- Opportunities to participate in research studies
- Information about cognitive decline and dementia
- Special programs for participants and their families

Please visit our new website at www.NYULMC.org/ADC for more information
Telephone: 212-263-8088
The Social Worker Role in the Research Center

As part of the team, the social worker provides:

- Education about memory loss and caregiving issues
- Referrals to appropriate community resources including senior centers and adult day care programs
- Information about housing options such as independent living, assisted living and nursing homes
- Safety issues related to wandering and alert devices
- Supportive counseling to deal with the diagnosis and the management of the disease.

Whether assisting with access to benefits or offering supportive counseling, social workers are the professionals available to help stabilize life around dementia care issues. Although social workers are knowledgeable about many caregiving issues, if there is something beyond their scope of knowledge, they can refer to a more appropriate source of support.

If you feel that you can benefit from the services of a social worker, ask for help. We are here to help you!

Physical Impairment and Alzheimer’s Disease
By Magda Tolea, PhD

Alzheimer’s Disease (AD) represents one of the most pressing public health concerns of our times. According to the Centers for Disease Control and Prevention, up to 5.3 million currently have AD. As the population ages, this number may double by the year 2050. As such, AD and related disorders will put great strain on the healthcare system as well as those affected, their families and caregivers. The single greatest risk factor for AD is age; the risk of AD doubles every five years starting with age 65, with almost 50% of older adults affected by age 85. It is no wonder that tremendous research effort is being put into understanding the factors that may be related to the development of AD. In addition to age, other risk factors include family history, education, head injury, and medical conditions such as diabetes and hypertension, but the goal is to identify risk factors that we can actually change.

One such risk factor for AD may be age-related physical impairment. Although how physical impairment may be related to a condition characterized mainly by cognitive clinical features may not be obvious, there has been growing evidence to suggest that decrements in physical functioning go hand-in-hand with cognitive impairment. In older adults, slower walking has been linked to both lower levels of and declines in cognitive domains such as executive function (problem-solving, decision-making, and multi-tasking activities). While the link between physical and cognitive function has been embraced by the scientific community, the direction of the association is still being debated. Is it that cognitive impairment is manifested as slower speed, or could it be that the slowing of walking speed may be a precursor of dementia?

A recent article accepted for publication by the Journal of the American Geriatrics Society provides some evidence in favor of the hypothesis that impairments in physical functioning may contribute to the development of cognitive decline/impairment. As part of the study conducted at the Knight Alzheimer’s Disease Research Center at Washington University in St Louis by a research team led by Dr. James Galvin, a neurologist who now leads the Pearl I. Barlow Center for Memory Evaluation and Treatment at New York University, 435 cognitively normal older participants were followed up for an average of 5 years. Physical function was measured with a tool that assesses tasks such as writing, using a spoon, lifting a light object, putting on a jacket, picking up a penny from the floor, turning 360 degrees, walking for 50 ft, rising from a chair, and balancing, all common physical activities used in everyday daily living. Cognitive performance was assessed with several clinical batteries including a detailed neurological examination, development of AD being determined based on the Clinical Dementia Rating (CDR), a commonly used dementia global rating system.
Physical Impairment and Alzheimer’s Disease

Continued from previous pg.

During the study period, 19% of participants were diagnosed with AD. The timing of the diagnosis was associated with initial physical function, development of AD being slower in participants with better physical performance. Presence of physical impairment was also found to predict a faster time to an AD diagnosis, even when the presence of other risk factors such as increasing age, gender, education, and the presence of an APOE ε4 allele, a genetic risk factor for AD, was accounted for. Therefore, by assessing the risk of developing AD in initially cognitively normal individuals based on their physical performance level at the beginning of the study, the authors were able to demonstrate that impairments in physical function can precede cognitive symptoms of AD by several years.

This opens the door for using physical performance tools, which could be easily administered on a regular basis in any physician’s office, to assess the risk of future cognitive impairment. Patients, whose physical function slows down beyond what would be expected for their age and is not otherwise explained, could be red flagged and followed more closely to assess their risk of developing dementia. Although not designed to assess the role of physical activity in the development of AD, the findings could also be interpreted to suggest a role for physical activity as a potentially protective factor against development of dementia. Being physically active has been associated with a lower risk of physical impairment at any age with benefits observed even among people into their nineties. Moreover, emerging evidence from clinical trials suggests that even short-term physical activity programs in older adults may provide improvement in cognition in those with memory complains. By encouraging and providing opportunities for individuals to be physically active throughout their lives, we may be able to help them postpone future development of dementia and/or slow down its progression once it sets in.


Sleep and Aging (continued from pg. 1)

Snoring becomes less common, and increased risk of mortality from stroke, hypertension, arrhythmias and diabetes, which are common in middle age, have not been consistently demonstrated in late life. The elderly seem to be more resistant to sleep changes and apneas but may complain of symptoms such as falls, confusion, and nocturia (the need to get up to urinate during the night) which might be attributed to causes other than sleep. Altogether, these studies suggest that older persons with SDB may experience apneas differently in terms of common symptoms, physiologic responses, and specific outcomes.

SDB and Alzheimer’s disease (AD) share a number of risk factors, including cardiovascular diseases (hypertension, diabetes, and stroke) and the ApoE4 genotype. Genome-wide association studies have suggested linkage between apneas and the region of chromosome 19 that also includes the ApoE4 allele (a strong genetic associate of sporadic AD), and there is evidence for interactive effects between ApoE4 carriers and SDB on cognitive function in older adults. Several studies have also shown increased prevalence of SDB in AD patients. Our preliminary studies, performed at the Center for Brain Health at the NYU School of Medicine, show for the first time in cognitively-normal elderly, that the severity of SDB is associated with some biomarker evidence from very early pre-symptomatic AD which raise the question as to whether AD causes SDB in the elderly, or if SDB acts as a factor promoting AD-neurodegeneration. We are currently performing studies investigating these important questions in normal elderly by examining the longitudinal associations between SDB and cognitive decline, with novel MR neuroimaging and cerebrospinal fluid biomarkers for neurodegeneration. Our ultimate goal would be to launch a pilot treatment study to prevent (or delay) AD in subjects with SDB.
**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, contact 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 65 or above, with and without memory complaints. Study participants will receive a comprehensive health screening and pencil and paper testing of memory and thinking abilities.  
For information, contact Licet Valois at 646-501-4213, licet.valois@nyumc.org

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**Early Diagnosis and Imaging Studies**

**Defining Cognitive Phenotypes of Parkinson’s Disease**
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 Gabriel Campion at 646-501-4212; gabriel.campion@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 Alexander Goldowsky at 212-263-7563; alexander.goldowsky@nyumc.org

**Maternal history of AD Predisposes Children to Brain Hypometabolism**
The goal is to determine whether young subjects (age 25-60) with and without a family history of AD show reductions in the brain’s metabolism of sugar and to measure a protein associated with AD, called amyloid, using PET imaging. In addition to PET imaging, all subjects will receive a comprehensive evaluation including a neurological and physical exam, MRI, memory testing, EKG, and laboratory blood-work.  
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, astrocitosis) 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
Research Opportunities

Perfusion Studies of Medial Temporal Lobe

Researchers at New York University Medical Center are seeking volunteers to participate in a study using arterial spin labeling and magnetic resonance imaging (MRI). This non-invasive method enables assessment of brain blood flow and vascular reserve. The study examines the effect of aging on hippocampal (memory center) perfusion assessed with arterial spin labeling MRI. This is a new imaging technique that uses magnetized water to image blood flow. Researchers seek to recruit volunteers between the ages of 55 and 90 who have a diagnosis of Mild Cognitive Impairment (MCI) or Alzheimer’s disease. Your participation will involve an MRI examination that takes 30 minutes. You will receive a $100 compensation for your participation.

For information, contact Dr. Henry Rusinek, NYUSM, Radiology Department 550 First Ave, NY, NY 10016, tel. 212-263-6537; hr18@nyu.edu

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 on 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.

For information, contact Ricardo Osorio at 212-263-3258; ricardo.osorio@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. For information, contact Nicole Spector at 212-263-7563; nicole.spector@nyumc.org

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.

For information, contact Catherine Randall at 212-263-7563; catherine.randall@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

Research Opportunities continue on next page
**Research Opportunities**

**Clinical Trials**

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.

**Clinical Phase II Study to Evaluate the Impact of Biomarkers of Resveratrol Treatment in Patients with Mild to Moderate Alzheimer’s Disease**

The goal of this study is to assess the effect of a fixed dose treatment of resveratrol on putative biomarkers of Alzheimer’s disease and to assess the safety and tolerability of treatment with resveratrol over a 12-month period in participants with mild to moderate AD. The study will also assess the effect of resveratrol on rate of whole-brain and hippocampal atrophy, as well as regional cortical thinning, using volumetric magnetic resonance imaging (MRI).

For information, 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 people with Alzheimer’s disease as well as healthy volunteers who are concerned about their memory 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 70+ years of age and be in good general health or have memory problems and are 55+ 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.

For information, 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 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.

For information, contact Brittany Cerbone at 212-263-5845; brittany.cerbone@nyumc.org

**Studies opening in 2013**

We anticipate starting several new investigational studies in early 2013 that will test the safety and efficacy of oral medications: Merck BACE inhibitor, Roche MAO-B Inhibitor, and Neuronix.

**Clinical Trials and Studies are also active at the Nathan Kline Institute in Rockland County**

**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.**

**Alzheimer’s Disease Neuroimaging Initiative-2 (ADNI)**

For information, contact Dr. Antero Sarreal at 1-800-521-8367, 845-398-6532 or 845-398-5582; asarreal@nki.rfmh.org
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, MSW 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)

The Science of Autopsies: What We Learn Together
By: Thomas Wisniewski, M.D. and Arline Faustin, M.D.

Brain donation is a wonderful and generous gift that a patient with Alzheimer’s or a related dementia disorder can give. This selfless gift provides significant benefits to both science and families in furthering the understanding, care and treatment of individuals with neurodegenerative disorders. The pathologic examination of brain tissue aims to gain a better idea of the causation of these neurological diseases, as opposed to relying only on a constellation of clinical symptoms to make diagnoses of dementia.

Over the years, evaluation of human postmortem brain tissue has uncovered morphological and biochemical changes that has led researchers to understand many of the mechanisms underlying Alzheimer’s disease (AD), and other neurodegenerative disorders, hence enabling better development of drugs and treatment regimens. However, there is still much more to discover, particularly with increased use of advanced studies of gene and protein expression (known as genomic and protenomic studies) in examining brain tissue of dementia patients, thus making brain donation essential and absolutely critical in furthering knowledge regarding Alzheimer’s and related dementias.
New to ADC

Arlene Faustin, MD

Dr. Faustin joined Dr. Thomas Wisniewski in July as Co-coordinator of the Brain Donation Program and Director of the Biorepository. She will also work with Dr. Galvin to enhance the NYU ADC’s Outreach Program.

Brittany Cerbone, BA

Brittany was hired in August as a Clinical Trials Coordinator to coordinate research participants in AD investigational drug trials and administer psychometric testing.

Christina Michel, BA

Christina began working in August as a Clinical Trials Coordinator. She helps manage phase 2-4 clinical trials for people with mild cognitive impairment to Alzheimer’s disease.

Gabriel Campion, BS

Gabriel was hired in September 2012 as a Research Data Associate. He is involved in psychometric exams and data collection, and is interested in Public Health.

2012 Walk to End Alzheimer’s

Employees and volunteers from the Silberstein Alzheimer’s Institute joined the 2012 Walk to End Alzheimer’s at Riverside Park in Manhattan on October 21st. Our team, “Aging with Excellence,” raised more than $1,200, this year, to support services for those affected by Alzheimer’s. We hope we will see you there next autumn!

What is it like to be in a support group? With Group Participant Jan

What’s a typical group session like?
We start off with a few exercises in our chairs to loosen up. At first, I wasn’t sure if I would like the exercises, but after trying it, I think it’s a great way to start. Afterwards, any group members can bring up a topic that is of interest, or that he or she is struggling with. It doesn’t have to be related to dementia, last time we talked about a good movie for a while. There’s a lot of laughing and humor. It takes me about 7 hours to get back and forth, so sometimes I can’t make it, but I come as regularly as possible, because it is worthwhile. If I miss a session, I don’t feel left out because the people and topics change.

What keeps you coming back?
It’s a good place to get ideas and support. Many times, I’ll be struggling with something; I will present it to the group and get great feedback. Another reason is that it is completely non-threatening. Everyone has some form of dementia and knows what it is like, so if you forget the word you are searching for, then you don’t feel bad. I get ideas of how to handle situations better than I would without the group’s input. For example, when I would want to go out, I would have trouble finding my belongings. The group members suggested putting all the items that I go out with in the same place every time I come into the house, and this simple suggestion really has helped me. Another example is, when I was retiring, I was unsure if I should have explained the diagnosis to my co-workers. The group suggested just saying that I have memory problems, instead of getting into specifics. This ended up being a good way for me to handle it. It’s also helpful to hear other people’s dilemmas, because you might not have even thought about something that someone else is dealing with, and when you end up dealing with it, you are more prepared.

What might you say to someone who is thinking of joining?
Give it a try, it will cost you nothing! Also, if you want to try it, come for at least 3 sessions, then you’ll get a good feeling of what it’s like. I’d also like to add that my wife has joined the peer group, which has helped her understand my condition and various solutions.
Brain donation is an important and generous gift, whether a person has Alzheimer’s disease or normal cognition. Examining brain tissue is the only method by which to make a definitive diagnosis of the cause of dementia. *If you or your family are interested in enrolling or want to know more about Brain Donation, Lynne Leung and Dr. Arline Faustin, our Coordinators, are available to help you. They can be reached at: (212) 263-5108 or lynne.leung@nyumc.org; arline.faustin@nyumc.org*

**Q:** Why is brain donation important?
**A:** Direct examination of brain tissue is the only way to definitively diagnose the type of dementia that a person with memory impairment has been afflicted with. The information gained through this program is leading researchers toward a greater understanding of these disease processes and to the discovery of potential effective treatments for them.

**Q:** Is brain tissue donation of value from individuals without memory impairment?
**A:** Yes. It is extremely important to study the brains of those individuals who do not have Alzheimer’s disease or other dementias. Brain donation from normal elderly persons allows researchers to determine the exact changes that are related to Alzheimer’s disease and other disorders and which changes are related to normal aging.

**Q:** Should I inform my Healthcare Proxy/next-of-kin of my decision to become a donor?
**A:** Yes. They are directly involved in the final consent process. We encourage you to discuss your interest in this program with them and urge them to call our coordinator, Lynne Leung, at 212-263-6262 to discuss any questions or concerns.

**Q:** Will funeral arrangements need to be altered?
**A:** No. Brain donation does not interfere with traditional or religious funeral arrangements. The procedure takes approximately 2 hours to complete and does not cause disfigurement that would prevent an open casket funeral.

**Q:** Will there be any cost?
**A:** If the donor had previously been evaluated here at NYU ADC, no costs other than those typically associated with funeral arrangements will be incurred by the family.

**Q:** What if the donor has never been evaluated at the NYU ADC?
**A:** Potential participants that have not been evaluated at our center are welcome to enroll in our Brain Donation Program. Understanding the medical history of the participant, including medications, dates of significant medical events and diagnoses/history pertaining to memory loss is important. An application requesting this information will be given to the interested participant and returned to us. We will then have a medical record on file which can be updated at any time. The coordinator can guide you/your family through this process.

*For donors that have not been evaluated at our facility, if it is possible to have the procedure done here at NYU, that cost will be covered by our program. If the procedure is done elsewhere, costs are incurred by the family. In both instances, the costs for transportation of the donor to and from the facility are incurred by the family.*
**Director:** Steven Ferris

**Executive Committee:** Mony de Leon, James Galvin, Iryna Lobach, Karyn Marsh, Mary Mittelman, Barry Reisberg, Melanie Shulman, Alok Vedvyas, Thomas Wisniewski

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Arlene Faustin

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Thet Oo  
Milena Perez  
Isabel Monteiro  
Carol Torossian  
Stella Karantzoulis  
Francoise Benarous  
Amanda Behrens-Horrell

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Dorothy Patterson  
Lynne Leung  
Milena Perez  
Ricardo Osorio

**Data Management and Statistics Core**
Iryna Lobach  
Alok Vedvyas  
Gaurav Vedvyas  
Wai Tsui  
Eugene Laska  
Elizabeth Pirraglia

**Education Core**
James Galvin  
Yael Zweig  
Licet Valois  
Crystal Quinn  
Gabriel Campion  
Magda Tolea

**Clinical Trials**
Dana Pogorelec  
Brittney Cerbone  
Christina Michel
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<td>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.</td>
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<td>Please make check payable to: Aging and Dementia Research Center and mail to: Aging &amp; Dementia Research Center Attn: Dorothy Patterson NYU School of Medicine 145 East 32nd Street, 2nd Floor New York, NY 10016</td>
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**ALZHEIMER’S DISEASE CENTER**
145 EAST 32nd STREET, 2nd FLOOR NEW YORK, NY 10016

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