

N.Y.C.A.R.E.

This insert is provided by New York Consortium for Alzheimer Research and Education (N.Y.C.A.R.E.) — a joint effort of the New York City Chapter of the Alzheimer’s Association and the Education and Information Cores of the Alzheimer’s Centers at Columbia-Presbyterian, Mount Sinai Medical Center and New York University School of Medicine — and funded by the National Institute on Aging.

Dementia with Lewy Bodies

What is it?

This disorder goes by many names. It has been called “lewy body disease,” “diffuse lewy body disease” and the current term, “dementia with lewy bodies.” It is a progressive dementia, which is relatively common. Dementia with Lewy bodies (DLB) is an increasingly recognized cause of primary degenerative dementia that may be more prevalent than has been suspected until recently. It commonly occurs in association with the Alzheimer’s disease pathology, but in its pure form, it may be relatively rare.

The age of onset for DLB is between 50 and 85. Some research suggests that patients with DLB decline at a faster rate than AD.

How do the symptoms differ from Alzheimer’s disease?

Although AD and DLB are both progressive dementias, the symptoms are different. Psychotic symptoms, especially visual hallucinations, are a common and prominent feature of DLB. These hallucinations are repetitive and described by patients as animals or people that appear to be real and are usually silent. In the early stages of the disease, patients are often aware that these images are not real. Patients with DLB also may exhibit physical symptoms. Typically these symptoms resemble the slowed movements, rigidity, stiffness, and the shuffling slow gait seen with parkinsonism. The level of alertness and ability to function of people with DLB changes on a daily basis. This is different from the minor fluctuations experienced by AD patients. Patients with DLB may experience loss of consciousness and frequent falls. Depression and disturbances of the deep stage of sleep are also common features of DLB. At later stages of the disease, patients may become incapacitated. In the final stages of DLB, symptoms resemble those of AD, and patients become increasingly incapable of performing basic activities of daily living, such as bathing and feeding themselves.

How is the diagnosis made for Dementia with Lewy body disease?

The work-up for DLB is the same as for AD. The most important part of making the diagnosis is the history of the symptoms listed above. If you are evaluated at a center that specializes in memory disorders you can expect to receive a variety of tests, which may include a neurological examination, blood tests, and brain imaging. The diagnosis can only be confirmed with an examination of brain tissue at autopsy if round deposits, the “Lewy bodies,” are present within the nerve cells.

Are there any treatments?

There is no specific treatment or cure for DLB. Many patients with DLB are treated with Aricept, Exelon and Reminyl, medications that are approved for the treatment of mild to moderate AD. These medications are used because some studies have suggested that they improve the cognitive and psychotic symptoms of DLB. Treating the hallucinations and other behavioral symptoms of DLB presents a challenge because these patients can be particularly sensitive to anti-psychotic medications. The most common side effects with these medications are confusion, drowsiness and worsening of the parkinsonism. Some studies suggest that the atypical anti-psychotic agents, such as Clozapine, Risperdal, Zyprexa and Seroquel, can be used to treat behavioral problems in patients with DLB. Some patients are also treated with levodopa (Sinemet) for the physical (motor) symptoms of DLB.

Are there any clinical trials?

A 12-week double-blind study of quetiapine (Seroquel) and donepezil (Aricept) for treatment of the behavioral disturbances in dementia with Lewy bodies is being conducted at many centers nationwide. This study is for patients who are age 50 and older. The eligibility for the study has recently been broadened to include patients diagnosed with AD who also have agitation or psychosis and parkinsonian symptoms. Patients diagnosed with Parkinson’s disease complicated by psychosis and dementia are also eligible to participate in this study. This trial, as well as a listing of other clinical trials being conducted by N.Y.C.A.R.E., are listed below.

For support and information for the person with DLB and their family members, please contact the Alzheimer’s Association, New York City Chapter at 212-983-0700.

Clinical Trials

Taub Institute At Columbia University

Alzheimer's Disease Treatment in African Americans

A 12-week study to evaluate the safety and effectiveness of donepezil (Aricept) in African-American patients, aged 50 and older, diagnosed with mild to moderate Alzheimer's disease is currently being conducted. There must be no prior use of Aricept. Participants who complete the study will receive a 12-week supply of Aricept free of charge. For more information, please contact Audrey Bauzo at 212-305-2077.

Comparison of Alzheimer's Disease Medications Study

We are seeking men and women, age 60 and older, for a study to evaluate the effects of galantamine (Reminyl) and donepezil (Aricept) on sleep and attention and gastrointestinal (GI) tolerance in patients with mild to moderate Alzheimer's disease. To learn more, please contact Ruth Tejada at 212-305-7661.

Dementia Prevention Study

Researchers at Columbia University are seeking healthy women, 65 years of age and older, who have a family history of Alzheimer's disease or memory problems for a four-year, placebo controlled study to determine whether estrogen can prevent memory loss. Participants will be paid. For more information, please contact Ruth Tejada at 212-305-7661.

Treatment of Behavior Problems in Lewy Body Dementia and Alzheimer's Disease Study

Psychosis (hallucinations or delusions) and agitation often accompany dementia. Unfortunately, when dementia is complicated by parkinsonian symptoms (such as rigidity, slowed movements, shuffling gait), the drugs commonly used to treat behavioral problems can worsen these parkinsonian symptoms. We are seeking men and women, age 50 and older, with Alzheimer's disease or dementia with Lewy bodies who also have parkinsonian symptoms with psychosis and/or agitation to participate in a 12-week study to determine the effectiveness of the atypical anti-psychotic quetiapine (Seroquel) and the cholinesterase inhibitor donepezil (Aricept) for the treatment of those behavior-related symptoms. For more information, please contact Ruth Tejada at 212 305-7661.

Cholesterol-Lowering Treatment and Alzheimer's Disease Study

Some evidence suggests a link between cholesterol and Alzheimer's disease-type changes in the brain. Other studies suggest lowering cholesterol may reduce these changes in the brain. We are seeking English and Spanish-speaking men and women, age 50 or older with mild to moderate Alzheimer's disease, to participate in a 12-15 month, placebo-controlled study to determine if the use of the cholesterol-lowering drug, simvastatin (Zocor), will be effective in slowing the progression of Alzheimer's disease. For more information, please contact Audrey Bauzo at 212-305-2077.

Antipsychotic Medication Treatment of Psychosis and Behavioral Dyscontrol in Alzheimer's Disease Study

Many people with Alzheimer's disease suffer from hallucinations, delusions, agitation, or aggression over the course of the illness. We aim to improve the quality of life of people with Alzheimer's disease, their families, and caregivers by studying the effectiveness of medications to treat these behavior-related symptoms. If interested, please contact Maddy Goodkind, Columbia University/NYSPI-RFMH at 212-543-5956.

Mood and Memory Study

A study examining the benefit of treatment for depression in people (age 50+) with combined depression and mild memory problems is currently being conducted. In those depressed patients whose memory problem persists, further treatment with medication to improve memory will be offered. If interested, please contact Jocelyn Cheng at 212-543-5067.

Other Studies

Memory Problems Study

We are seeking English and Spanish speaking participants, 50 years of age or older with memory problems, to participate in a long-term follow-up study examining the clinical and brain imaging markers for the early diagnosis of Alzheimer's disease. If interested, please contact Dr. Matthias Tabert, Ph.D. at 212-543-5046.

Normal Aging and Memory Study

We are seeking men over the age of 70, in good health without memory problems, who wish to participate in a research study on understanding normal aging and memory, may earn \$10/hr at Columbia-Presbyterian Medical Center (Research Foundation For Mental Hygiene). No medication is prescribed. For more information, please contact Maddy Goodkind at 212-543-5956. Spanish-speaking participants welcome.

Genetic Linkage Study

We are seeking Caribbean Hispanic families from the Dominican Republic for a study to identify genes that may increase the risk for AD. If you have at least two living family members diagnosed with AD, and are interested in participating in this study, please call Vincent Santana at 1-877-636-5677 or Jennifer Williamson at 212-305-4655.

The Gift of Knowledge - Brain Donation Program

Brain donation allows valuable information to be obtained regarding normal aging and diseases that affect memory. This information may be useful towards the goal of developing more effective treatment strategies. If you or a family member wish to learn more about this program, please call Arlene Lawton, RN, at 212-305-9086.

Ageing and Dementia Research Center The William and Sylvia Silberstein Institute for Ageing and Dementia New York University School Of Medicine Current Studies

CLASP-AD [Cholesterol-Lowering Agent to Slow Progression of AD]:

Patients age 50 and older with mild to moderate Alzheimer's disease (AD) have an opportunity to participate in a study to evaluate whether an FDA approved cholesterol-lowering medication slows the progression of symptoms. Participants must not currently be receiving or requiring treatment to lower cholesterol. This is a 21-month trial. Concurrent use of other medications for the treatment of AD is allowed. For more information, please contact Robyn Waters at 212-263-3417.

Homocysteine:

Patients age 55 and older with mild to moderate Alzheimer's disease (AD) have an opportunity to participate in a study to evaluate whether a Vitamin B Complex can slow the clinical progression of the disease. A blood protein called homocysteine is elevated in AD, and people with high levels of this protein seem to have a greater risk of developing the disease. The purpose of this study is to test whether lowering levels of homocysteine with B vitamins can slow further decline in patients with AD. This is an 18-month trial. Sixty percent of the participants will randomly receive a Vitamin B Complex, while forty percent receive placebo (inactive substance). Concurrent use of other medications for the treatment of AD is allowed. For more information about this pharmaceutical study, please call the Clinical Trials Coordinator, Maria Vlassopoulos at 212-263-5708.

COGNIShunt™ Study:

Ventricular shunts similar to those used in patients with hydrocephalus may also slow the course of Alzheimer's disease. We are beginning recruitment of mild to moderate severity Alzheimer's disease patients (ages 62 - 85) to receive shunt placement surgery. Patients selected for shunt surgery will be followed for 18 months: the first 9 months will be a randomized placebo-controlled phase. The concomitant use of other Alzheimer's disease medications will be permitted during this study. For more information, please contact Jessica Lam at 212-263-5709.

Longitudinal Study of Normal Aging, Mild Cognitive Impairment (MCI) and Alzheimer's Disease (AD):

Participants receive a comprehensive diagnostic evaluation and are re-evaluated every two years. The goal of this project is to improve early diagnosis and to better understand the clinical course and causes of age-related cognitive decline and Alzheimer's disease. For more information, please call Emma Shulman at 212-263-5756.

Biomarkers for Early Diagnosis of Alzheimer's Disease:

Normal elderly, individuals with mild cognitive impairment (MCI) and people with Alzheimer's disease (AD) may volunteer to donate blood samples and cerebrospinal fluid (CSF). The goal is to validate biochemical indicators of AD that may lead to an early diagnostic test for this disorder. Reimbursement for time and effort will be provided. For further information, please contact Elissa Thorn at 212-263-7563.

Brain Donation Program:

Participants at the Silberstein Institute are eligible to participate in a free autopsy program that provides families with a definitive diagnosis and contributes to important research on the causes and treatment of brain aging and Alzheimer's disease. For further information, please contact Dr. Sadia Faiz at 212-263-5108.

Upcoming Studies

In the coming months there will be several new studies of interesting treatments for people with mild to moderate Alzheimer's disease and mild cognitive impairment (MCI). Participants will receive close medical follow-up by physicians and other healthcare professionals. For further information about future studies, please call 212-263-5708.

Enrollment will soon begin for a new study including education and support for people caring for a parent with moderate stage Alzheimer's disease. For information about this study, please call Cynthia Epstein at 212-263-1056 or Alicia Pierzchala at 212-263-7619.

Mount Sinai Alzheimer's Disease Research Center Studies For Healthy Volunteers and Alzheimer's Patients

Guanfacine Study:

The goal of this 21-week study is to determine if treatment with Guanfacine, in combination with Aricept, Reminyl or Exelon, will lessen cognitive impairment and behavioral disturbance associated with Alzheimer's disease more effectively than Aricept, Reminyl or Exelon alone. Patients are eligible for one year of free treatment upon completion of the study. For more information, please contact our ADRC research coordinator at 212-241-8329.

CATIE Study:

Many patients with Alzheimer's disease suffer from agitation, delusions, and hallucinations. In the hopes of improving quality of life for those with AD and their families, we are conducting a nine-month study to study the effectiveness of certain FDA-approved medications to treat those symptoms. Medication and medical care that are part of the study are provided at no cost. For more information, call our ADRC research coordinator at 212-241-8329.

A Trial of an Insulin-Sensitivity Enhancing Agent to Improve Cognition in Alzheimer's Disease:

This study uses an insulin-regulating medication to enhance the activity of insulin degrading enzyme so that it can break down β -amyloid proteins. People with Alzheimer's disease cannot properly break down β -amyloid proteins, which accumulate to form plaques in the brain. This medication could interfere directly with the disease process by blocking the formation of plaques and hopefully prevent the development and progression of the disease. Patients with Alzheimer's disease are eligible. For more information, please call our ADRC research coordinator at 212-241-8329.

Statin Study:

We are seeking patients with Alzheimer's disease to participate in this multi-center, randomized, double-blind, placebo-controlled trial of simvastatin, a cholesterol-lowering drug. This study will test whether this drug can slow the progression of symptoms in AD. For more information, contact our ADRC research coordinator at 212-241-8329.

Protective/Risk Factors for Alzheimer's Disease in Healthy Adults:

This study aims to identify biological factors that might either predispose or protect individuals from developing Alzheimer's disease. The 2-3 hour interview would be completed at the subjects' home. A small blood sample is drawn to allow investigators to examine possible protective factors. Participants will be compensated for their time. Men and women who are 85+ years old with no memory impairment or dementia will be eligible for the study. If interested, please call the Family Studies Office at 718-584-9000, Extension 2713.

MRI Study for AD Patients and Healthy Adults:

The aim of this study is to investigate the connection between brain functioning and cognitive testing. Subjects receive an MRI (Magnetic Resonance Imaging) test while answering some memory questions. Transportation is provided to the Bronx Veteran Affairs Hospital and participants will be compensated for their time. Men and women who are 70+ years old with a diagnosis of Alzheimer's disease, as well as those without memory problems, will be eligible for the study. For information, call the Family Studies Office at 718-584-9000, Extension 2713.

Brain Tissue Donation Program:

The goal of this program is to improve existing treatments and to develop new treatments for AD, which is not possible without the generosity and altruism of individuals who partner with Mount Sinai by participating in our brain donation program. Therefore, men and women, with and without memory impairment are eligible to provide their "intent" to consent for this program. There are several benefits to participation and we have specially trained staff available to discuss these benefits, the donation process, and any related concerns that you and your family might have.

Note: Spanish-speaking participants are welcome in all studies. All study participants receive reimbursement for any related expenses. Participants without AD receive monetary compensation for their time.

If you are interested in any of the above research studies,
please contact the Alzheimer's Disease Research Center at [212-241-8329](tel:212-241-8329).

Mount Sinai also has Satellite clinics specializing in AD and other Memory Disorders located at:

Elmhurst Hospital in Queens: (718) 334-3983

Bronx VA Medical Center: (718) 584-9000 x5199

Phelps Memorial Hospital in Westchester: (914) 366-3669