
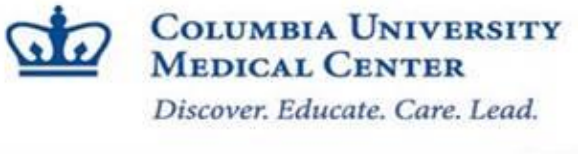


For more information on all the clinical trials and observational studies available or questions regarding research study participation, please contact:

**Betina Idnay, RN**

Research Nurse

Phone: (212) 342-5615

Email: bsi2102@cumc.columbia.edu

# Interested in Research?

## *The Alzheimer's Disease Research Center (ADRC)*

COLUMBIA UNIVERSITY
IRVING MEDICAL CENTER

### About the ADRC:

- Columbia's ADRC is a pioneer in promoting research on Alzheimer's Disease and related dementias.
- There are different types of research opportunities at the ADRC and the associated Taub Institute for Research on Alzheimer's Disease and the Aging Brain, including:
  - **"observational studies"** focused on understanding causes and effects of dementia in patients, caregivers, and family members
  - **"clinical drug trials"** testing new drug treatments to improve symptoms or prevent or affect course of dementias
- Research commitment varies: some studies require only one or two visits, while others continue over multiple years.

### Who can participate?

- Studies recruit many types of participants, including:
  - Adults who do not have memory problems
  - Adults with some memory concerns
  - Adults who have been diagnosed with Alzheimer's disease or another dementia

### How do I participate?

- If you are interested in opportunities to participate in research here at the ADRC or Taub Institute, please fill out our Research Interest Questionnaire:
  - https://tinyurl.com/ADRC-Research-Interest
- You can also view a listing of some of the ongoing clinical and observational studies on our website: http://columbianeuroresearch.org/taub/ct-current-trials.html

# Neurodegeneration-Associated Psychiatric Syndromes
# Columbia University Research Study
# Dr. Edward Huey

## Overview

Columbia University Medical Center is currently running a research study to look at how dementia (like Alzheimer's disease) can affect mood and behavior, and to better understand the relationship between the brain, mood and behavior. We are accepting people with dementia, such as Alzheimer's disease, Frontotemporal dementia, Huntington's disease, and other related dementias, as well as people who do not have dementia. At the study visit, participants will meet with a physician and study staff, who will ask them about recent changes in mood and behavior. This visit also includes a Magnetic Resonance Imaging (MRI) scan.

## Participation is Voluntary

As with all research, this is a voluntary study, and you do not have to participate if you do not want to. Also, you may stop participating at any time.

## Alternatives

You do not have to participate in this study. If you are currently enrolled in a different study at Columbia, your enrollment in that study will not be affected by whether or not you chose to participate in this study.

## Procedures

- Come in to Columbia for a 4- to 5-hour long study visit
- Identify a study partner, who may be a family member or friend, to come in with you during the visit or talk with us by phone about your recent mood and behavior
- Answer questions about your medical and psychiatric history
- Be given brief paper and pencil tests of thinking and memory
- Complete questionnaires and be interviewed about your current emotions and behaviors
- Undergo blood draw for routine laboratory tests (10 ml or 2 teaspoons)
- Undergo an MRI, which will last up to 1 hour
- Complete a brief smell identification test

## Risks

This study includes some risks and discomforts (which will be further elaborated in the consent form):

- This research study involves a blood draw. Risks of having blood drawn are soreness and/or a black and blue mark at the site from where the blood is drawn.
- In this research study, we will ask you to report on and complete questionnaires regarding your mood and behaviors. You may feel uncomfortable or embarrassed completing some questionnaires. If you do not wish to complete a particular questionnaire, you will not be required to do so.
- You will be asked to undergo an MRI in this research study. There is no evidence that radio waves associated with MRI are harmful. However, it may be the case that you will feel the need to leave the MRI scanner due to claustrophobia or discomfort from lying on your back. If you experience any discomfort and wish to stop the scan, you can inform the MRI technologist and he or she will stop the scan immediately.

## Benefits

This research study is not meant to benefit you directly. However, you will receive $50-$100 for your participation in the study.

## Contact

You may contact the research teams, at HueyResearchTeam@cumc.columbia.edu and 212-305-3187 or 212-304-7944.

**Síndromes psiquiátricos asociados con la neurodegeneración**

**Estudio de investigación de la Universidad de Columbia**

**Dr. Edward Huey**

## Visión general

El Centro Médico de la Universidad de Columbia (Columbia University Medical Center) actualmente está realizando un estudio de investigación para observar cómo la demencia (como la enfermedad de Alzheimer) puede afectar el estado de ánimo y el comportamiento, y para comprender mejor la relación entre el cerebro, el estado de ánimo y el comportamiento. Aceptamos personas con demencia, como la enfermedad de Alzheimer, la demencia frontotemporal, la enfermedad de Huntington y otras demencias relacionadas, al igual que personas que no tienen demencia. En la visita del estudio, los participantes se reunirán con un médico y el personal del estudio, quienes les preguntarán acerca de los cambios recientes en el estado de ánimo y el comportamiento. Esta visita también incluye una resonancia magnética (MRI, por sus siglas en inglés).

## La participación es voluntaria

Al igual que con todas las investigaciones, este es un estudio voluntario, y usted no tiene que participar si no lo desea. Además, puede dejar de participar en cualquier momento.

## Alternativas

No tienes que participar en este estudio. Si actualmente está inscrito en un estudio diferente en Columbia, su inscripción en ese estudio no se verá afectada por la decisión de participar o no en este estudio.

## Procedimientos

- Venga a Columbia para una visita de 4 a 5 horas de duración.
- Identifique a un compañero del estudio, que puede ser un miembro de su familia o amigo, para que lo acompañe durante la visita o hable con nosotros por teléfono sobre su estado de ánimo y comportamiento recientes.
- Responda preguntas sobre su historial médico y psiquiátrico.
- Reciba exámenes breves de papel y lápiz de pensamiento y memoria.
- Complete cuestionarios y sea entrevistado sobre sus emociones y comportamientos actuales.
- Sométase a una extracción de sangre para las pruebas de laboratorio de rutina (10 ml o 2 cucharaditas).
- Sométase a una resonancia magnética (MRI), que durará hasta 1 hora.
- Complete una breve prueba de identificación del olor

## Riesgos

Este estudio incluye algunos riesgos y molestias (cuales serán elaborados en el formulario de consentimiento):

- Este estudio de investigación implica una extracción de sangre. Los riesgos de la extracción de sangre son dolor y / o una marca negra y azul en el sitio de donde se saca la sangre.
- En este estudio de investigación, le pediremos que reporte y complete cuestionarios sobre su estado de ánimo y comportamientos. Puede sentirse incómodo o avergonzado al completar algunos cuestionarios. Si no desea completar un cuestionario en particular, no se le pedirá que lo haga.
- Se le pedirá que se someta a una resonancia magnética (MRI) en este estudio de investigación. No hay evidencia de que las ondas de radio asociadas con el MRI sean dañinas. Sin embargo, puede darse el caso de que sienta la necesidad de abandonar el escáner del MRI debido a claustrofobia o incomodidad por acostarse sobre su espalda. Si experimenta alguna molestia y desea detener el examen, puede informarle al tecnólogo de MRI y él o ella lo detendrá de inmediato.

## Beneficios

Este estudio de investigación no pretende beneficiarlo directamente. Sin embargo, recibirá una compensación de $50-100 por su participación en el estudio.

## Contacto

Puede comunicarse con el equipo de investigación al HueyResearchTeam@cumc.columbia.edu y al 212-305-3187.

# Join a Research Study:

## Neurodegeneration-Associated Psychiatric Syndromes

### (Principal Investigator: Edward Huey, M.D.)

## About the research

- Seeking participants for an observational research study **looking at how dementias** can affect mood and behavior
  - Participation involves **one voluntary, 2-3 hour remote visit** to answer questions about recent moods and emotions and **one voluntary 2-3 hour in-person visit** to complete an MRI scan and blood draw
  - Participants will be compensated $50-$100


## Who can participate?

- This study is recruiting **a wide range of participants**, including healthy controls, people with mild cognitive impairment, and people diagnosed with dementia <u>who also</u>
  - Are between 40-90 years old
  - And speak English or Spanish.

## How do I participate?

- If you are interested in becoming involved in this study or learning more, please contact the research team at **HueyResearchTeam@cumc.columbia.edu** or **212-305-3187**.

Columbia University
Medical Center

# Usted puede ayudar a encontrar la cura del Alzheimer

**El estudio familiar de la influencia genética en la enfermedad de Alzheimer (EFIGA) esta buscando voluntarios mayores de 50 años, con o sin problemas de la memoria que deseen ayudarnos a conocer mas sobre los factores de riesgos y genéticos relacionados con esta enfermedad.**

Si está interesado en participar en el estudio o desea obtener más información escribanos a **efiga@cumc.columbia.edu** o llamenos al **212-305-2309**

**La participación es gratis e incluye resultados de un recuento sanguíneo completo, colesterol, presión arterial y una prueba de memoria.**

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Esta investigación no ofrece tratamientos. La misma se lleva a cabo bajo la dirección del Dr. Richard Mayeux, MSc, en el GH Sergievsky Center y la Universidad Columbia.

212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309 212-305-2309

## ¿Quien puede Ayudar?

Estamos buscando familias con por lo menos 3 personas que puedan donar sangre, incluyendo:

- Dos hermanos o hermanas que tengan la enfermedad del Alzheimer.
- Otra persona en la familia mayor de 50 años el cual pueda tener problemas de memoria o mayor de 60 sin ningún problema de memoria.

Los participantes pueden residir en cualquier parte de los Estados Unidos, Puerto Rico y Republica Dominicana.

**¿Por que son tan importantes las familias?**

Encontrar genes no es fácil. Cada persona puede tener alrededor de 30,000 genes, para encontrar los que incrementan el riesgo de padecer Alzheimers, es como buscar una aguja en un pajar. Por eso necesitamos la ayuda de familias. Miembros de familias, particularmente hermanos y hermanas comparten material genético. Mientras mas hermanos, hermanas y familiares cercanos hay en una familia, con y sin problemas de memoria, mayor es el chance de encontrar genes que contribuyan a la enfermedad de Alzheimer.

**Para mas información, llame a:**


**Vincent Santana, MBA**

**Senior Officer of Research**

**Columbia University**

**Tel. 212-305-6342**

**Fax 212-342-5144**

**Cell 347-752-7165**

**vcs2103@columbia.edu**

**630 W. 168th Street, P&S Box 16**

**New York, NY 10032**


# Estudio Familiar Influencia Genética en Alzheimer

Columbia University New York/República Dominicana

(809) 473-4616, EFIGA@SERGIEVSKY.ORG, (212) 305-6342

**¿Tiene usted en su familia 2 o mas hermanos viviendo con la enfermedad de Alzheirmer?**

**Si es así, Necesitamos su ayuda!**

Como parte de una familia afectada con la enfermedad de Alzheimer, usted sabe que tan importante es encontrar la manera de prevenir esta devastadora enfermedad. El primer paso es detectar quienes están en riesgo de desarrollar la enfermedad. Para esto, necesitamos su ayuda.

Si 2 o mas hermanos o hermanas en su familia esta viviendo con la enfermedad de Alzheimer u otro problema de memoria relacionado, esperamos que considere participar en el Estudio Genético de Alzheimer. Familias como la suya puede que tengan las respuestas para este importante estudio.

Invitamos a su familia a unirse a nosotros para conocer mas sobre las causas de esta enfermedad y como podríamos prevenirla en próximas generaciones.

**¿QUE ES EFIGA?**

EFIGA es un estudio que tiene por meta encontrar factores de riesgos que estén asociados con la enfermedad de Alzheimer.

**¿QUE TIENEN QUE HACER LOS PARTICIPANTES?**

Queremos hacer la participación de usted y su familia lo mas fácil posible. Se les requerirá a los participantes una muestra de sangre, completar una entrevista en persona y hacerse un examen medico, incluyendo un examen de la memoria. Las familias serán re-evaluadas cada dos años aproximadamente.

**¿QUE VA A PASAR CON MI SANGRE Y CON LA INFORMACION SOBRE MI SALUD?**

Toda la información colectada y muestras de sangre serán codificadas y guardadas de forma estrictamente confidencial. Las muestras de sangre no tendrán nombres, fecha de nacimientos, direcciones, teléfonos o numero de seguro social. Los investigadores protegerán cuidadosamente toda la información genética.

**¿HAY ALGUN COSTO PARA PARTICIPAR?**

No hay ningún costo para participar. En todo caso, algunos gastos (como costo de parqueo u otro tipo de transporte) pueden ser pagados por el estudio.

**¿TODOS LOS MIEMBROS DE FAMILIA TIENEN QUE VIVIR CERCA PARA PARTICIPAR?**

No. Miembros de familias participantes pueden vivir en cualquier parte de Estados Unidos, Puerto Rico y/o Republica Dominicana. Un equipo de investigadores lo visitara en su casa.

**¿COMO SE VA A BENEFICIAR MI FAMILIA?**

Recibirá actualizaciones sobre este y otros estudios de manera regular. Tendrá la oportunidad de conversar con personas hacienda el estudio. Recibirá referencias de servicios de apoyo para pacientes y familias si lo necesita. Pero mas importante, tendrá la oportunidad de ayudar a futuras generaciones.

**¿COMO PUEDO OBTENER MAS INFORMACION?**

Para mas información sobre el estudio, por favor contáctenos a:

**Sin cargo:**

**Republica Dominicana: 1-200-1646**

**USA y Puerto Rico: 1-800-243-5828**

**Email: efiga@sergievsky.org**

Si su familia ha sido afectada por esta enfermedad, por favor acompáñenos. Comparta esta información con sus familiares. Converse con ellos sobre el estudio.

**LA INVESTIGACION ES NUESTRA MAYOR ESPERANZA PARA UN MUNDO SIN ALZHEIMER.**

# Are 2 or More Siblings in Your Family Living with Alzheimer's Disease?

# If so, we need your help!

If anyone in your family is living with AD, you know how important it is to find a way to prevent it. **The Alzheimer's Disease Genetics Study** is a nationwide research study to find the genes that play a role in late-life Alzheimer's disease (AD) – to learn more about the causes of AD, and how to treat or prevent it.

**Families who have 2 or more siblings (brothers or sisters) with late-life AD hold the key to this important research.**

The AD Genetics Study seeks families who have ***at least 3 members*** who can donate blood, including:

- 2 siblings (brothers or sisters) who developed AD after age 60, and
- Another family member over age 50 who may have memory loss OR a family member over age 60 who does not have any memory loss.

Participants can live anywhere in the U.S. and people of all racial or ethnic backgrounds are welcome.

**If this sounds like your family,** we invite you to join us to find out more about AD, what causes it, and how we might prevent it for future generations.

For more information, call toll-free: **1-800-526-2839**
In New York, call **212-305-4655**

**Research is our best hope for a world without Alzheimer's disease.**

The AD Genetics Study is sponsored by the National Institute on Aging (one of the National Institutes of Health, U.S. Department of Health & Human Services) and supported by the Alzheimer's Association.

U.S. Department of Health & Human Services

National Institute on Aging
National Institutes of Health

**Alzheimer's Association**

JOHNS HOPKINS MEDICINE

Approved December 17, 2019

ALLFTD is a multisite research project aimed at understanding the changes in brain function that occur as a result of frontotemporal lobar degeneration (FTLD) syndromes. FTLD syndromes can include bvFTD, bvFTD with ALS, PPA, PSP, or CBD. Some forms of FTLD are genetic, while others are not. ALLFTD is interested in all forms of FTLD.

We can learn about changes in your brain a variety of ways, including a clinical examination, memory and thinking tests, and MR imaging of your brain. We also measure different proteins in your blood or cerebral spinal fluid (CSF) that we think change in response to disease progression.

If you are interested in helping us learn more about FTLD and you've been diagnosed with a FTLD syndrome or are at risk due to your family history, please consider participating in our ALLFTD Longitudinal Study.

## Study Sites

### Sites

Case Western Reserve University, Cleveland

Cleveland Clinic Lou Ruvo Center for Brain Health, Las Vegas

Columbia University in the City of New York

Houston Methodist Hospital, Nantz National Alzheimer Center

Johns Hopkins University, Baltimore

Massachusetts General Hospital, Boston

Mayo Clinic, Jacksonville

Mayo Clinic, Rochester

Northwestern University, Chicago

UCLA, Los Angeles

The University of Alabama at Birmingham

The University of British Columbia, Vancouver

University of California, San Diego

University of California, San Francisco

The University of North Carolina at Chapel Hill

University of Pennsylvania, Philadelphia

University of Toronto

University of Washington, Seattle

Washington University in St. Louis

### Contact your site:

Find more information at www.allftd.org/sites.

# ALLFTD Longitudinal Study

ALLFTD
ARTFL LEFFTDS Longitudinal Frontotemporal Lobar Degeneration

JOHNS HOPKINS MEDICINE

Approved December 17, 2015

## Who is eligible to participate in the ALLFTD Longitudinal Study?

You're being asked to participate in the ALLFTD Longitudinal Study because you've either:

1. Been diagnosed with a FTLD syndrome like bvFTD, bvFTD with ALS, PPA, PSP, or CBD
2. Are from a family with a mutation in a gene known to cause FTLD (such as C9orf72, MAPT, and GRN)
3. Have a significant family history of FTLD suggesting a familial genetic mutation.

If you are from groups 2 or 3, you don't have to have symptoms to participate and you don't need to know your mutation status to participate.

## What happens in the ALLFTD Longitudinal Study?

The ALLFTD Longitudinal Study is an annual visit to the clinic, each lasting 2–3 days. We will have you complete some questionnaires, meet with a clinician for a neurological exam, have your blood drawn, some memory and thinking questions, and a MRI. If you're willing to do a lumbar puncture, we will also collect your cerebrospinal fluid.

## Where can I find more information about the study?

You can find more information about the study on our website at www.allftd.org.

## I am interested in participating. What do I do next?

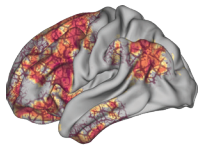
Please tell your neurologist that you'd like to participate in the ALLFTD Longitudinal Study. You can also find contact information for ALLFTD site study coordinators at www.allftd.org and can also email a coordinator to let them know you'd like to join. We suggest you choose the site most convenient for you.

## FTLD Genetics

Familial FTLD (f-FTLD) occurs in about 30% of FTLD cases where multiple members of a family are affected. This occurs due to changes in the genetic code called mutations, which are associated with a high risk of developing FTLD during a person's lifetime. These mutations follow an autosomal dominant inheritance pattern, meaning each child of someone with a mutation has a 50% risk of inheriting the mutation. Mutations that cause f-FTLD can present with any FTLD syndrome, and in a given family each affected individual can potentially present with a different syndrome. There are three gene mutations commonly associated with f-FTLD (*MAPT:* microtubule associate protein tau; *GRN:* progranulin; and *C9orf72:* chromosome 9 open reading frame 72), however through research studies like this one we are learning about other mutations that cause f-FTLD.

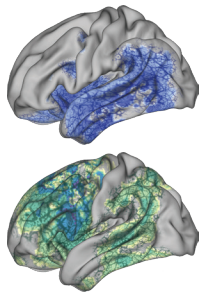
## FTLD Syndromes

### Behavioral Variant of Frontotemporal Dementia (bvFTD)



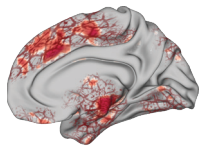
Early symptoms in bvFTD usually include loss of interest in previously enjoyed activities (apathy), loss of empathy, loss of knowledge about how to behave in social situations (disinhibition), and fixations or obsession about certain topics or ideas.

### Primary Progressive Aphasia (PPA)



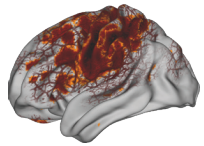
The main symptoms are early and progressive language difficulties. Spoken and written words are affected. Words lose their meaning and there can be issues recognizing objects and people in the semantic variant, or there is difficulty in getting words out so speech seems hesitant and effortful in the non-fluent variant.

### Progressive Supranuclear Palsy (PSP)



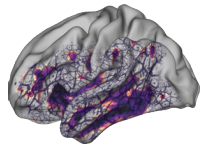
Those with PSP have difficulty moving combined with other problems including social-emotional function, cognitive functions, or language, depending on which parts of the brain are involved. Movement problems include stiffness and slowness of the body, poor balance with falling, and trouble moving the eyes.

### Corticobasal Syndrome (CBS)



CBS is identified by movement difficulty combined with other problems including social-emotional function, cognitive functions, or language challenges. Early symptoms are worsening stiffness that affects one side of the body (arm or leg) and similar language, cognitive, or social-emotional changes as those seen in bvFTD and PPA.

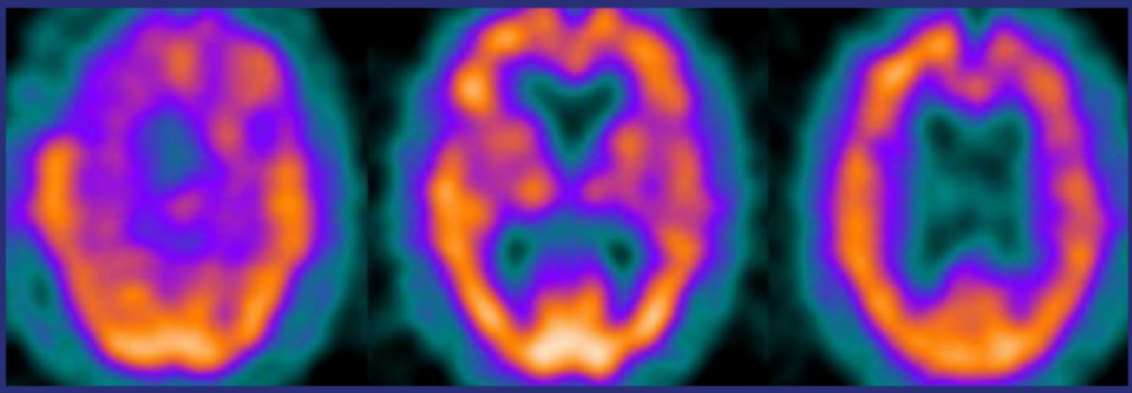
### bvFTD with Amyotrophic Lateral Sclerosis



Often referred to as *motor neuron disease*, ALS (sometimes called Lou Gehrig's disease) is caused by degeneration of nerves in the brain and spinal cord that control muscles. The main symptoms are weakness, twitching, and atrophy (shrinking) of the muscles in the limbs, torso, neck and face, usually starting in one part of the body and spreading to others.

COLUMBIA UNIVERSITY
MEDICAL CENTER

*Center of Excellence for Alzheimer's Disease*



## Multi-service Center for Patients and Medical Professionals

### Patient Services

- Memory and Cognitive evaluations
- On-site blood testing, biomarker, and imaging services
- Social work referrals and assistance
- Genetic Counseling
- Individualized case review by our multi-interdisciplinary team
- Access to research studies and clinical trials

### Education & Training for Medical Professionals

- One on one case consultation with a dementia specialist
- Educational lectures and conferences discussing, Alzheimer's Disease and related disorders such as Lewy Body, Parkinson, Frontotemporal, and Progressive Supranuclear Palsy dementias
- Community and public awareness activities

***Thorough, accessible dementia evalautions for early detection***

**(212) 305 2316**
**AlzheimerCenter@cumc.columbia.edu**
**https://cead.cumc.columbia.edu**


COLUMBIA UNIVERSITY
MEDICAL CENTER
*Center of Excellence for Alzheimer's Disease*

## MEMORY EVALUATIONS

To schedule an evaluation, or to make a referral, please call:

(212) 305-2316

*Location:*
*710 West 168th St, 3rd Fl*
*New York, NY 10032*
*(Corner of Ft. Washington Ave & West 168th Street)*

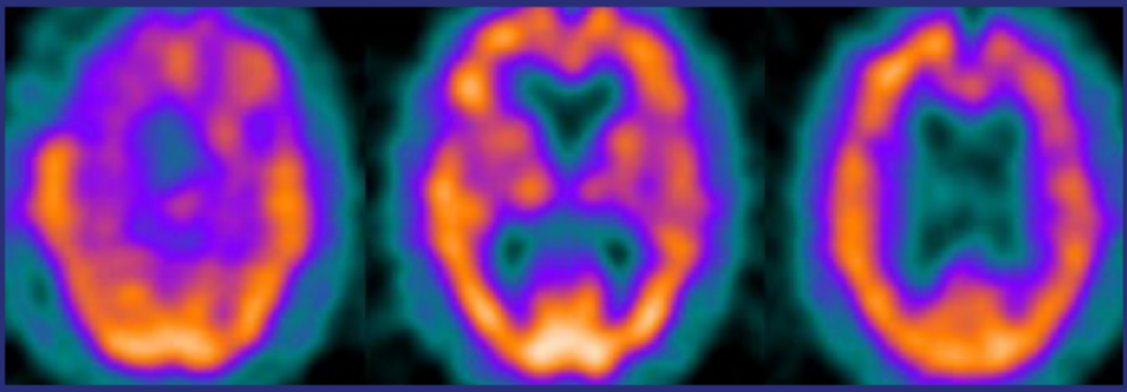
## Reasons To Seek An Evaluation

1) Difficulty finding words or names
2) Forgetfulness causing one to miss appointments
3) Difficulty managing finances
4) Getting lost while driving or traveling by public transportation
5) Changes in personality and or increased mood swings
6) Previous diagnoses of unspecified dementia

**This Center of Excellence for Alzheimer's Disease is supported in part by a grant from the New York State Department of Health.**

COLUMBIA UNIVERSITY
MEDICAL CENTER

*Center of Excellence for Alzheimer's Disease*



# Centro de Servicios Múltiples para Pacientes y Profesionales Médicos

## Para los Pacientes

- Evaluaciónes de memoria
- Análisis de sangre e imágenes del cerebro en el mismo lugar
- Asistencia de trabajo social y referimientos
- Consejería Genética
- Revisión de casos individualizados por nuestro equipo interdisciplinario
- Acceso a estudios clínicos

## Educación Médica y Formación para Profesionales de Salud

- Consulta de caso con un especialista de demencia
- Conferencias educativas sobre Alzheimer, Lewy Body, Parkinson, Demencia Frontotemporal, Paralisis Supranuclear Progresivo e otras demencias relacionados
- Actividades de conocimientos público

***Evaluación compresiva de la demencia que es accesible y esencial para la detección temprana***

**(212) 305 2316**
**AlzheimerCenter@cumc.columbia.edu**
**https://cead.cumc.columbia.edu**


COLUMBIA UNIVERSITY
MEDICAL CENTER
*Center of Excellence for Alzheimer's Disease*

# EVALUACIÓNES DE MEMORIA

Para hacer una cita o un referimento, llame al:

(212) 305-2316

*El Instituto de Neurología*
*710 West 168th St, Tercer piso*
*New York, NY 10032*
*(En la esquina de la calle de Fort Washington y West 168)*

## Razones Para Hacer Una Evaluación

1) Dificultad para encontrar palabras o nombres
2) Olvido que causa que pierda citas
3) Dificultad para administrar las finanzas
4) Perderse mientras conduce o viaja en transporte público
5) Cambios en la personalidad y/o aumento en variación de estado de ánimo
6) Diagnósticos previo de demencia, no específica

**CEAD es apoyado en parte por una iniciativa financiada por donación del Departamento de Salud del Estado de Nueva York que sirve a los cinco condados de la ciudad de Nueva York.**

COLUMBIA UNIVERSITY
MEDICAL CENTER

# BRAIN DONATIONS INSTRUCTIONS

At time of death, please call us immediately.

Scott M. Reid, MA at C: 201-951-6661

- OR -

Lawrence S. Honig, MD, PhD, FAAN at:
(212) 305-9194, press 1

COLUMBIA UNIVERSITY
MEDICAL CENTER

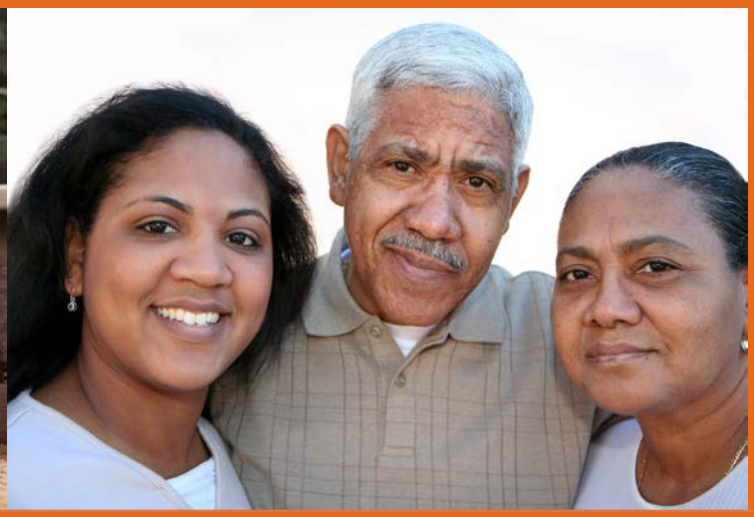
# INSTRUCCIONES PARA LA DONACIÓN DEL CEREBRO

En caso de defunción llámenos inmediamente:

Scott M. Reid, MA: 201-951-6661

- O -

Lawrence S. Honig, MD, PhD, FAAN
(212) 305-9194, (selecionar 1)



# EARLY-ONSET ALZHEIMER'S DISEASE (EOAD) STUDY

## GOAL OF THE EARLY-ONSET ALZHEIMER'S DISEASE FAMILY STUDY

The ultimate goal of the EOAD Family Study is to identify genetic factors that increase the risk of early-onset Alzheimer's disease and are possible targets for the development of therapeutic interventions. To be able to do so, the EOAD Family Study recruits, evaluates and follows families who have multiple members with early-onset Alzheimer's disease. To date, over 87 families across the U.S. are participating in this effort.

The Early-onset Alzheimer's Disease Family Study aims to foster a culture of greater cooperation and sharing of clinical and biological resources among researchers worldwide. Virtually every major genetic study of early-onset Alzheimer's disease will be able to utilize information, patients and controls from this dataset. Though many studies of Alzheimer's disease (AD) have identified genetic mutations linked to the disease, these mutations only explain ~10% of EOAD cases! With your participation, this study can lay the groundwork for identifying the genetic links to the remaining 90% of unexplained cases of early-onset Alzheimer's disease.

## OUR PROGRESS RELIES ON THE FAMILIES PARTICIPATING IN THIS RESEARCH!

The families that participate in this study have the opportunity to become the foundation of a groundbreaking array of genetic discoveries about early-onset Alzheimer's disease. By studying the incidence of disease in families affected by EOAD, we can greatly improve our understanding of the various genes, genetic variants (subtle, individual differences in DNA), and related genetic pathways leading to disease. We are also sharing this information (in a de-identified manner) with scientists worldwide to encourage more rapid progress in terms of identifying, treating, and even preventing EOAD, for all those impacted by this devastating disease.

## MOVING FORWARD…

While the discoveries that have been made about inheritance patterns associated with genetic mutations linked to AD risk are extremely exciting and incredibly important, much work remains to be done.

**Project Coordinator:**
**Penelope Baez**
Tel: 212-305-1527
Email:
pib2102@cumc.columbia.edu

What are the genetic factors underlying the many unexplained cases of familial early-onset Alzheimer's disease? What additional genetic factors are involved in the development of AD? What is the impact on disease risk of inheriting one or more of the identified variants?

What is the impact of the identified genetic variants in disease in offspring of families with multiple affected individuals? Why do certain individuals who carry high-risk genetic variations seem to escape disease—what is protecting them? These are just a few of the questions researchers around the world can investigate with the EOAD Family Study dataset to find a cure for this disease.

## HOW CAN YOU HELP US FIND A CURE FOR THIS DISEASE?

**If anyone in your family under the age of 65 is experiencing memory problems or dementia, they may be suffering from early-onset Alzheimer's disease. If you think your family meets these criteria and would like to participate in this research, please contact our study coordinator Penelope Baez (Tel: 212-305-1527). Also, if you know of others who may qualify, please have them contact us as well.** Study participation can be completed over the phone or in person. The evaluation will take about 1 to 1½ hours per person and includes:

1. **Blood Sample (2 tbsps.):** This sample is used to create de-identified cell lines that will be banked at our blood bank here at Columbia University Medical Center. (Blood kits will be made available to over the phone participants.)

2. **Brief Neuropsychological Assessment:** This verbal and visual memory test will take approximately 45 minutes to one hour.

3. **Medical History:** A research physician will collect basic medical information on you and your family. We may also request that you and your family members authorize the release of medical records to our research team, from any physician(s) seen for memory problems.

If you and your family decide to participate, we hope that you will take great pride in the fact that the EOAD Family Study dataset will be a preeminent resource, both nationally and internationally, for scientists from academia and industry to continue to make headway into the genetic complexities of EOAD. Indeed, the tremendous contribution you and your family members will make to the field of Alzheimer's disease research cannot be understated.

**We thank you!**

Christiane Reitz, MD, PhD
Columbia University

*"Hopefully, somewhere along the way the cycle will be broken."*

*– Research Participant*

# NATIONAL INSTITUTE ON AGING LATE ONSET ALZHEIMER DISEASE (NIA-LOAD) STUDY

*Annual Update* Winter 2020

## Dear NIA-LOAD Families,

The NIA-LOAD family based study has long set the standard for data sharing in the field of Alzheimer's disease research, and continues to do so. As a result, researchers both nationally and globally have generated novel discoveries and, in turn, shared their data with other researchers, thereby facilitating scientific discovery and the potential for therapeutic breakthroughs! Of course, none of this would have been possible, nor would we be able to continue to grow this invaluable resource without the continued support of you, our incredibly brave and committed NIA-LOAD participants and families!

As part of our recent National Institute on Aging Research Centers Coordinating Network (U24) Award, we have now setup an NIA-LOAD website*, to help us expand our recruitment efforts and facilitate even greater data sharing among AD researchers. We are also moving into evaluating participants via Zoom—a HIPAA compliant video service where privacy is guaranteed. We will be piloting this idea later this year—more info to come!

We are also pleased to report that, since our 2019 newsletter, we have completed follow-up evaluations with 1137 participants and have enrolled 472 new individuals across all sites! Enrollments in our Voluntary Brain Donation Program** continue to grow. Published research studies involving the NIA-LOAD cohort now total 98 papers and counting!

In this issue, we are featuring a Q&A with NCRAD Project Manager Kelley Faber, MS, CCRC, in an effort to address any questions you might have about how your biological samples are processed, stored, and shared with other investigators to facilitate more productive and efficient research on AD and related disorders. Included in Kelley's Q&A is a detailed explanation of why it is imperative that we continue to receive additional samples to enable this vital research. Please consider contacting your site to donate again if you can!

Thank you, as always, for your ongoing commitment to NIA-LOAD!

Richard Mayeux, MD, MSc, Columbia University

*http://www.columbianeurology.org/research/research-partners/national-institute-aging-late-onset-alzheimer-s-disease-family-based-study-nia-load-fbs
**http://columbianeuroresearch.org/taub/brain-donation.html

## ABOUT NIA-LOAD

The inception of the National Institute of Aging Late Onset Alzheimer's Disease (NIA-LOAD) Family Study in 2002 started a trend of greater cooperation and sharing of clinical and biological resources among researchers worldwide. Virtually every major genetic study of Alzheimer's disease (AD) has included patients and controls from this dataset. It is arguably the most widely used AD genetics dataset in the world, with at least 98 research publications, to date. These publications can be found here: **http://columbianeuroresearch.org/taub/NIA-LOAD-Publication-2020-finalized.pdf.**

YOU, the families of NIA-LOAD, are the foundation of this extraordinary array of Alzheimer's disease genetic discoveries. We hope that you take great pride in the fact that your contribution to the NIA-LOAD Family Study enables scientists, both nationally and internationally, to continue to make headway into the genetic complexities of AD, toward truly effective, targeted therapeutic interventions!

# The Essential Role of NCRAD in AD Research

## A Q&A with NCRAD Project Manager Kelley Faber, MS, CCRC

*What is NCRAD and how does it relate to the NIA-LOAD Family Study?*

The National Centralized Repository for Alzheimer 's Disease and Related Dementias (NCRAD) is an NIA-funded biorepository that currently receives, banks, and distributes biospecimens from over 60,000 participants in 40 studies, including the NIA-LOAD study. NCRAD began working with the NIA-LOAD family study in 2002. To date, we have received samples from over 7,000 individuals across approximately 2,700 families. The NCRAD team (*pictured above*) works with the NIA-LOAD study to collect blood samples from which NCRAD is able to obtain DNA, immortalized lymphoblastoid cell lines (LCLs), and peripheral blood mononuclear cells (PBMCs). Both the NIA-LOAD clinical data and these biological samples are highly sought after by researchers within the Alzheimer's disease field.

*Once samples from participants in the NIA-LOAD Family Study are received by NCRAD, how are they handled?*

When NIA-LOAD Family Study samples are received at NCRAD, they are handled with the utmost care. The samples are shipped directly to our laboratory from the study sites in a de-identified manner, which means that no identifying information like name, birth date, etc. is included on the labels or with the paperwork.

When samples are received at NCRAD, they are logged into our database and the blood is processed into DNA or cells depending on how the sample was collected. Our laboratory and coordination staff run many different quality control checks on both the samples and on the data that accompanies the samples to ensure accuracy at every step. Maintaining the highest quality samples is NCRAD's top priority.

*What is the average "shelf-life" for blood samples, and why is it important that NIA-LOAD continue to recruit new participants, as well as routinely request new samples from current participants?*

The blood drawn into the lavender top tube is processed into DNA upon receipt at NCRAD. There is a limited amount of DNA that can be created from each tube of blood. The extracted DNA is stored frozen and will last indefinitely frozen.

The blood collected into the green top tubes is used to create a cell type called peripheral blood mononuclear cells (PBMCs). This is a new sample type for the NIA-LOAD study. This type of cell line only creates a limited number of cells. The cells are stored frozen at NCRAD and last indefinitely frozen.

**Contact Your NIA-LOAD FAMILY STUDY Site Coordinator:**


**Case Western Reserve University**
Sara Kennedy sek67@case.edu

**Columbia University:**
Izri Martinez imm2129@cumc.columbia.edu
Sebastian Ibarra jsi2109@cumc.columbia.edu
212.305.2349; 212.305.2309

**Indiana University**
Kelly Horner kjhorner@iupui.edu
Ashley Vetor abozell@iu.edu
800.526.2839

**NCRAD at Indiana University**
Kelly Farber kelfaber@iupui.edu
Milena Petkov mipetkov@iu.edu
800.526.2839

**Mayo Clinic (Rochester, MN)**
Christine Hanzel Hanzel.Christine@mayo.edu
507.284.1324; 507.293.6429

**Rush University**
Corey Woods Corey_J_Woods@rush.edu
312.942.0050

**University of Miami**
Larry Deon Adams ladams4@med.miami.edu
305.243.9375

**North Carolina State University**
Takiyah Starks tdstarks@ncat.edu
888.248.2808; 336.285.2172

**University of Pittsburgh**
Elise Weamer weamerea@upmc.edu
412.692.2741

**University of Texas Southwestern**
Amy Browning amy.browning@utsouthwestern.edu
214.645.1972

**University of Washington**
Sarah Payne sarah.payne@va.gov
Adrienne Jankowski adrienne.jankowski@va.gov
206.277.1024

**Washington University**
Joanne Norton nortonj@psychiatry.wustl.edu
Jennifer Gentsch gentsch@psychiatry.wustl.edu
800.747.2979; 314.747.3753


However, in the case of both the DNA and PBMC samples, as investigators request these for use in their research, our stores becomes depleted. Therefore, we do sometimes need to request additional blood for DNA and PBMCs to be collected.

*What is the process for researchers outside the NIA-LOAD Family Study to gain access to de-identified samples from the NIA-LOAD cohort, for their own research purposes?*

In order for researchers to gain access to the de-identified NIA-LOAD samples, they must apply to the NCRAD Biospecimen Review Committee (BRC). The NCRAD BRC has been established to review applications seeking access to samples to ensure that the samples are appropriately distributed and matched with the best research. The NCRAD BRC consists of a panel of experts in the field of dementia research. The review committee considers the qualifications of the researcher requesting the samples, the project the requestor is planning to use the sample for, and the quantity of sample available for each sample at NCRAD.

Once an application is approved, the researcher requesting the samples completes paperwork with NCRAD to confirm the proper handling of the samples in their laboratory. When the researcher completes their analysis, they are required to share their results with the research community. This ensures that the data from the samples is as valuable as possible.

*What would you like NIA-LOAD participants and their family members to know about how their participation through NCRAD is enabling vital research?*

The NIA-LOAD samples and data provide an unprecedented resource for studying the genetics of late-onset Alzheimer's disease. To date, we have sent out nearly 68,000 aliquots of DNA and cell lines to more than 50 different investigators all over the country and the world. Because of your generosity, researchers have made tremendous strides in understanding this complex disease, which we hope will help us develop improved treatments and, ultimately, a cure.

**GO GREEN!**

**Please help us save some trees by signing up to receive future NIA-LOAD updates by email instead! Simply email your site coordinator with email contact information for you and your family members!**

## WE STILL NEED YOUR HELP!

1. **We are recruiting Mexican American and Central and South American individuals with a family history of Alzheimer's disease who are willing to participate as research subjects**.

2. **We are also still recruiting African American participants, and children of current participants who are age 50 or older.**

In addition, we are continually recruiting families with three or more affected individuals. **If you know of others who may meet our study criteria, please have them contact us!** Study participation can be completed over the phone or in person. The evaluation will take about 1 to 1½ hours per person and includes:

**1. Blood Sample (2 tbsps.):** This sample is used to create cell lines that will be banked at our blood bank here at Columbia University Medical Center. (Blood kits will be made available to over the phone participants.)

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*"Hopefully, somewhere along the way the cycle will be broken."*

*— NIA-LOAD Research Participant*

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**[COMPANY NAME]**
[Street Address]
[City, ST ZIP Code]

**[Recipient Name]**
[Street Address]
[City, ST ZIP Code]



# Are you a caregiver or healthy adult looking to help further the research on cognitive impairment and Alzheimer's disease?

## Participate in a new research study:

- Eligible participants are healthy adults, aged 60-85 years
- Help us assess new ways of testing memory and attention
- Receive a free research MRI scan
- May receive monetary compensation for your time

**If interested, please call:**

**Sophie Bell at 646-774-8691**

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*Discover. Educate. Care. Lead.*

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THE STUDY IS CONDUCTED AT THE NEW YORK STATE PSYCHIATRIC INSTITUTE/COLUMBIA UNIVERSITY MEDICAL CENTER AND IS FUNDED BY THE NATIONAL INSTITUTE ON AGING.

JOHNS HOPKINS
MEDICINE

NYSPI IRB Approved
7609
2/26/2020 -> 2/25/2021

Approved March 13, 2018

# Seeking individuals with Alzheimer's disease who experience agitation

The Escitalopram for Agitation in Alzheimer's Disease (S-CitAD) study is a 12-week trial of escitalopram taking place at

## Memory Disorders Clinic at the New York State Psychiatric Institute

## The S-CitAD Research Study is looking for volunteers who:

- Have been diagnosed with Alzheimer's disease
- Experience feelings of irritability, restlessness, frustration, or anger
- Have a study partner who can participate in the study

All participants receive:

- Free parking at each visit
- Psychosocial counseling provided to all eligible participants
- All visit procedures administered at no cost

## Call 646-774-8671 for more information

Protocol: IRB00148995 | PI: Constantine Lyketsos

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NYSPI IRB Approved
7537
8/7/2020 -> 8/6/2021

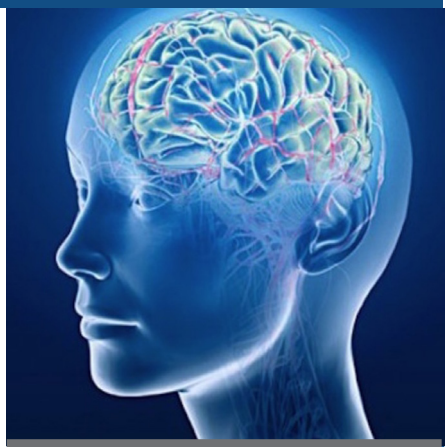
# The FIRST EVER Anti-Viral Clinical Trial for Alzheimer's Disease

This research is funded by the National Institutes of Health (NIH)

Viruses may cause or contribute to the pathology of Alzheimer's disease. This research treatment study at the **MEMORY DISORDERS CLINIC** is the first-ever clinical trial to address this hypothesis.

This study includes:

- Brain imaging
- Clinical assessments
- Anti-viral research treatment with pills



**CONTACT US:**
**646.774.8638**
**40 Haven Avenue**
**New York, NY 10032**

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8/7/2020 -> 8/6/2021

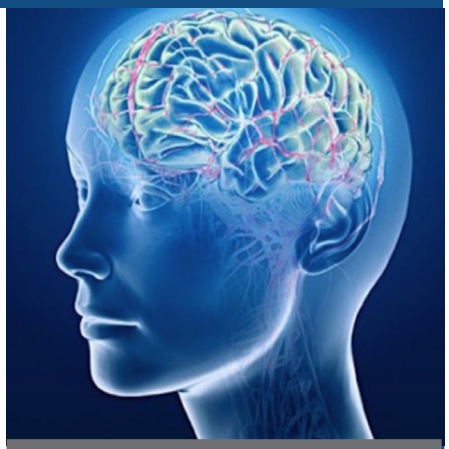
# La PRIMERA investigación clínica antivirulenta para la enfermedad de Alzheimer

La investigación se funda por los Institutos Nacionales de Salud (NIH)

Es posible que los virus puedan contribuir a la patología de la enfermedad de Alzheimer. Este estudio de tratamiento en **la Clínica de Trastornos de Memoria** es el primer estudio para abordar esta hipótesis.

Este estudio incluye:

- Imágenes del cerebro
- Evaluaciones clínicas
- Tratamiento anti virulento con pastillas



**Llame el número**

**646-774-8668**

**40 Haven Avenue**
**New York, NY 10032**

# MEMORY EVALUATIONS

Are you or a loved one worried about having Alzheimer's disease? Receive a free memory evaluation and access to current research studies. Evaluations may include:

- Neuropsychological testing for memory and cognition.
- Formal assessment of behavioral changes.
- A second opinion on a diagnosis of Alzheimer's disease.
- Counseling and education in available services and studies.

**We provide free phone consultations and memory evaluations**

For more information, please call

646-774-8668 or 646-774-8665

## MEET OUR TEAM

**Davangere Devanand, MD**
Co-Director
Professor of Clinical Psychiatry and Neurology

**Gregory Pelton, MD**
Assistant Professor of Clinical Psychiatry

**Edward Huey, MD**
Assistant Professor in Psychiatry and Neurology

**Nancy Kerner, MD**
Attending Physician and Sleep Disorders Specialist in Geriatric Psychiatry

**Deborah Deliyannides, MD**
Assistant Clinical Professor of Psychiatry

**Terry Goldberg, PhD**
Professor of Medical Psychology

**MDC @ NYSPI**
**1051 RIVERSIDE DRIVE**
**NEW YORK, 10032**
**COLUMBIAPSYCHIATRY.ORG/RESEARCHCLINICS/MEMORY-DISORDERS-CLINIC**



# The Memory Disorders Center

Columbia University Medical Center

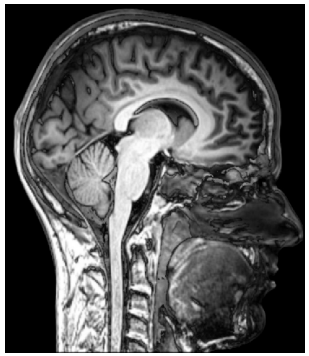
New York State Psychiatric Institute

# PARTICIPATE IN A RESEARCH TREATMENT STUDY



RESEA

## Anti-viral Therapy in Alzheimer's Disease



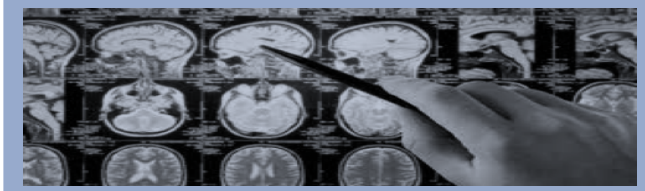
The "Anti-viral therapy in Alzheimer's disease" study is investigating the efficacy of treating patients with mild Alzheimer's disease with the U.S.A marketed generic anti-viral drug Valtrex (valacyclovir). Valacyclovir at 2g to 4g per day, is being compared to matching placebo in the treatment of 130 mild AD patients (65 valacyclovir, 65 placebo) who test positive for herpes simplex virus-1 (HSV1) or herpes simplex virus-2 (HSV2). The study is a randomized, double-blind, 18-month Phase II proof of concept trial.

## Development of Novel Measures of Cognition & Function for Alzheimer's Disease Prevention Trials

This study aims to determine how effective different cognitive and functional tests commonly used in clinical trials are, in testing memory, executive function, and attention. Eligible participants are non-cognitively impaired, healthy adults (ages 60-85 years) who will be followed over the course of 12 months. Participants will receive either novel more experimental measures that are computerized or the older more established measures that involve paper and pencil tests. This study is funded by the NIA, a division of the NIH.

## Escitalopram for Agitation in Alzheimer's disease

This NIA funded 24-week study is designed to examine the effectiveness and safety of Escitalopram in combination with a psychosocial intervention as treatment for agitation in patients with Alzheimer's disease. In this double-blind study, you may receive oral medication: Escitalopram or placebo. Patients are allowed to receive other specific psychiatric medications if needed during the study, and will be closely monitored by physicians who specialize in memory disorders. Patients will receive 12 weeks of follow-up, after completing the 12-week double blind trial.



## Interaction of OSA and APOE e4 on Risk of Early Onset Cognitive Impairment

This study includes a one-time, 90 minute sleep-cognitive research study visit, aimed to evaluate the interaction between sleeping disturbances and memory function. This NIH funded study will clarify the effect of obstructive sleep apnea (OSA) and the APOE ε4 gene on cognitive performance among participants with Mild Cognitive Impairment (MCI). Eligible patients include those patients who have a sleep problem and cognitive or memory concerns
(ages 55+). This study is also recruiting healthy adults. Participants will complete a detailed medical history questionnaire and neuropsychological evaluation.

## Research Treatment

The team offers participation in a variety of research studies. These include investigational studies for normal controls, Mild Cognitive Impairment (MCI) and Alzheimer's disease (AD), agitation in patients with Alzheimer's disease, and new approaches for making an early diagnosis of Alzheimer's disease. The Memory Disorders Center is the main research component of the Columbia University Alzheimer's Disease Research Center (ADRC), and is one of 28 specialized ADRCs funded by the National Institute on Aging, which is part of the National Institutes of Health (NIH).

Participation in research is completely voluntary. If after your evaluation, you wish to be referred elsewhere or be followed at our Neurological Institute's private office, this is 100% your decision. We can also provide multi-faceted resources and references to programs or other trials as decided by you and our clinical physician.

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# Estudio de Investigación sobre la Memoria y el Envejecimiento

**¿Cuál es el propósito del estudio?** Investigar cuales puedan ser los riesgos para los problemas de memoria y la enfermedad de Alzheimer entre los adultos mayors de edad.

## ¿Quién puede participar?

- Hispanos- hombres y mujeres
- De 65 en adelante
- Personas sin la enfermedad de Alzheimer
- Vivir en el alto Manhattan (codigo postal: 10032, 10033, 10034, 10040)

## Procedimientos:

- Por via Telefonica
- En el Centro Medico Columbia University o en su casa: Visita en persona (3 horas):
- Evaluación de la memoria y la cognición Visita en persona o de manera remota (3 horas):
- Entrevista médica y una pequeña muestra de sangre se extraerá

* No se le pedirá que tome medicamentos.

**Se le compensara por su tiempo, y habra un pago adicional por los gastos de viaje.**

Si está interesado en participar en el estudio, comuníquese con el Coordinador del Proyecto al 212-305.1130.

Esta investigación está financiada por el Instituto Nacional sobre el Envejecimiento

**Aprobado por el CU-IRB # AAAO9804**

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# Research Study on Memory and Aging

## What is the purpose of the study?

To look for risk factors for memory problems and Alzheimer's disease among older adults

## Who can participate?

- Men and women ages 65 and older
- People without diagnosed memory problems
- Live in Upper Manhattan area (zip codes: 10032—10033, 10034, 10040)

## Procedures:

- By phone, at Columbia University Medical Center, or your home
- In-person visit or remotely (3 hours):
  - Assessment of memory and cognition
    - Medical interview and a small sample of blood will be drawn

**You will be compensated for your time, as well as an additional pay for travel expenses.**

*This is not a drug study. You will *not* be asked to take medicine.

**If you are interested in participating in the study, please contact the Project Coordinator at 212-305.1130.**

This research is funded by the National Institute on Aging

Approved by the **CU-IRB # AAAO9804**