

## How *are* Participant Rights Protected?

Patient confidentiality is protected in all studies. Participant names and other unique identifying information are never used in study reports. Participants have the right to drop out of the study at any time.

Informed consent laws require that all information on possible risks and benefits be provided to participants. In some cases, a patient with dementia may not be able to provide informed consent because of problems with memory and confusion. In these cases, an authorized representative (usually a family member) may give permission for the person to participate.

An Institutional Review Board (IRB), made up of physicians, researchers and community advocates, must approve and monitor all clinical research studies. The IRB ensures that the rights of participants are protected.

## Steps in a Research Study

*First, there is usually a screening process to explain what is involved in the study and to determine whether a person is a good match for the study being conducted.*

*Next, there is a baseline visit involving a full physical and neurological examination, laboratory studies, and paper and pencil tests.*

*Then, follow-up visits occur at regular intervals.*

## How Can *You* Help?

The University of Utah Center for Alzheimer's Care, Imaging and Research has research opportunities for patients with age-related problems and for healthy individuals, who may participate in a study's control group.

If you or someone you care about is interested in helping us learn more about memory problems, please contact the Center's Clinical Study Coordinator for more information at (801) 581-4944. Our Coordinator, Rebecca Mesley, can answer any questions you may have about clinical research studies or currently available research opportunities.

## Questions *about* Research?

*Please contact Rebecca Mesley,  
Clinical Study Coordinator:  
Tel (801) 581-4944*

The University of Utah  
Center for Alzheimer's Care,  
Imaging & Research  
650 Komas Drive #106-A  
Salt Lake City, UT 84108-1225

[www.utahmemory.org](http://www.utahmemory.org)



The University of Utah

Center for Alzheimer's Care, Imaging & Research

## Clinical Research Studies for Memory Loss and Aging

Center *for* Alzheimer's Care,  
Imaging *and* Research

Department *of* Neurology  
School *of* Medicine

# Why *is* Research Important?

*Research is our only hope to help millions of Americans with Alzheimer's disease (AD) or other dementias. While tremendous progress has been made in the past 20 years, there is much left to discover. Researchers may be on the brink of significant breakthroughs in the prevention, diagnosis and treatment of Alzheimer's.*

*Recent research advances have included the identification of genes that may put people at risk for AD, exciting progress in the development of an Alzheimer's vaccine, and refinements in brain imaging techniques that allow for earlier diagnosis.*

*Researchers at the University of Utah Center for Alzheimer's Care, Imaging and Research (CACIR) are currently looking for eligible research study participants.*

## What *is* a Clinical Research Study?

Clinical research studies are conducted to find out if a potential treatment is safe and effective. They have become an increasingly important part of research in Alzheimer's disease and related disorders.

Some clinical research studies involve experimental drugs or procedures that are not otherwise available as medical treatments.

Other studies examine existing drugs or procedures that are currently used in other medical conditions to determine if they are also helpful for memory loss.

Participating in a clinical research study is a big step. Individuals and their families should carefully consider all the possible benefits and risks before agreeing to participate.

## Benefits of Participation

- Regular contact with dementia experts that can provide a wide range of information, support and referrals to other services
- Help others in the future by contributing to medical research

## Risks of Participation

- There may be side effects associated with the treatment
- The treatment may not be effective for the participant

## Questions to Ask Before Participating

- What is the purpose of the study?*
- Why do researchers believe the treatment may be effective?*
- What kinds of tests and treatments are involved?*
- How do the benefits, side effects and risks compare with my current treatment?*
- How will the research study affect my daily life?*
- How long will the study last?*
- Who will pay for the treatment?*
- Will I be paid for my participation?*
- How will I know if the treatment is working?*
- Will results of the study be provided to me?*
- Who will be in charge of my care?*