

What Questions Should I Ask Before Participating in a Clinical Trial?

- ❖ What is the main purpose of the study?
- ❖ How long is the study going to last?
- ❖ What procedures will I undergo if I participate?
- ❖ Do I have to pay for participating?
- ❖ Will I receive any reimbursement?
- ❖ What is the research experience of the physician and study staff?



Institute for Neurodegenerative Disorders
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Directions:

From I-95 North or South -

Exit 47 to Route 34 West to exit 3. Turn right onto York Street and take the next right onto George Street. The Temple Medical Building is located at the corner of George and Temple Streets.

From I-91 South -

Exit 1 to Route 34 West to exit 3. Turn right onto York Street and take the next right onto George Street. The Temple Medical Building is located at the corner of George and Temple Street.

FREE PARKING is available in the Temple Medical Garage, in the Temple Street Garage, and by valet parking at the entrance to the Temple Medical Building. Bring your ticket to the receptionist.



For more information contact

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For Adults with Down Syndrome

What does the future hold?



**Ask About Participating in the
Down Syndrome Mindful Aging
Research Initiative**

Join the Fight



NEIRB Approved

7/17/09

Sponsored by the
Institute for Neurodegenerative Disorders

What is the *Down Syndrome Mindful Aging Research Initiative*?

- The purpose of this research initiative is to develop brain imaging methods that may detect changes in the brain that occur with aging.
- Due to the presence of a substance called amyloid in the brain, adults are at greater risk to develop cognitive changes and eventually dementia as we age.
- Premature aging occurs in people with Down syndrome, putting adults at greater risk of developing amyloid in the brain at an earlier age.
- Through development of PET imaging procedures, we may be able to detect amyloid in the brain prior to the onset of signs and symptoms.
- Similar PET imaging procedures are currently available for other diagnostic purposes.
- Through early detection of disease and the use of neuroprotective compounds as they are developed, it may be possible to stop the progression of brain disease.

What safeguards are in place for the study participant?

- The U.S. Federal Agencies, including the Food and Drug Administration (FDA) and the National Institutes of Health (NIH), oversee the medical research in the U.S.
- Institutional Review Boards (IRBs) oversee the centers where clinical research studies are conducted.



- **Participants must be able to communicate a willingness to take part in the research initiative.**
- **Participants must have a willing and stable caregiver to accompany them during study visits.**



Participants will receive a \$400 stipend

Learn more about us at www.indd.org

What are the benefits to participating in research?

This research may not benefit the participant directly, however, most people participate because they would like to:

- Partner with researchers dedicated to advancing healthy aging in Down syndrome.
- This important research may help answer questions about memory loss.
- Have the opportunity to undergo a neurological exam by experts in the field.

Who is conducting this study?

The Institute for Neurodegenerative Disorders (IND) is an independent, nonprofit research institute located in New Haven, CT.

Our research team is committed to developing strategies to prevent and cure neurologic diseases including Parkinson disease, Alzheimer disease, and other dementias.

Our goal is to develop simple screening tests to assess subjects at risk for disease so that treatment can be initiated as early as possible.