

Early signs of Fronto-Temporal Degeneration

Behavioral variant:

- Changes in social behavior (lack of restraint, indifference, ..)
- Repeating behaviors or routines
- Changes in eating habits
- Poor decision making or organization

Changes in language ability:

- Difficulty in speaking
- Loss of meaning of words
- Difficulty to recall words
- Difficulty understanding single words or longer sentences

What are the study facts?

- Study participation is voluntary.
- Joining the study will not affect your healthcare or insurance.
- All information is confidential.
- There is no cost to participate.
- Participants may withdraw from the study at any time.
- Travel to the research center is not required.
- Although we are unable to provide individual results to families, we do send out periodic newsletters about research progress to participants.



A LOOK INSIDE

Frontotemporal Degeneration

FRONTOTEMPORAL DEGENERATION RESEARCH
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How do I join the study?

Call the Study Coordinator toll free at:
1-877-686-6444

or email us at:

FTD-HIHG@MIAMI.EDU

For additional information, please visit our website:
www.hihg.org

John P. Hussman Institute for Human Genomics
University of Miami Miller School of Medicine
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CONTACT US FOR MORE INFORMATION OR TO ENROLL
YOUR FAMILY IN THIS RESEARCH STUDY.

This study is conducted with support from the National Institutes of Health and the Alzheimer's Association.

This University of Miami IRB-approved (20070307) research study is conducted in accordance with federal guidelines and current US laws.

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WHAT IS FRONTOTEMPORAL DEGENERATION?

Frontotemporal degeneration, the most common form of dementia before the age of 60, affects over 60,000 people in the United States. It affects portions of the brain that control behavior, language and/or movement. Though it frequently is misdiagnosed as Alzheimer disease, it presents with different initial symptoms, generally starts earlier and is less common and far less known. Currently, although treatments are available, there is no cure for frontotemporal degeneration. Research studies show that individuals with a family history of frontotemporal degeneration have a greater chance of developing the disease.

Investigators at the John P. Hussman Institute for Human Genomics (HIHG) want to help understand the genetics of frontotemporal degeneration. Researchers hope to reduce the risk factors for developing this disease and reverse the growing threat of frontotemporal degeneration among all people.

WHAT IS OUR RESEARCH GOAL?

HIHG researchers strive to identify the genetics of frontotemporal degeneration. As we identify the genetic components underlying the disease, we will be able to improve diagnostic and treatment options. With your help, the HIHG can continue this search.



RESEARCHERS AND FAMILIES WORKING TOGETHER CAN FIND THE GENETIC CAUSES OF FRONTOTEMPORAL DEGENERATION.

WHAT DOES PARTICIPATION INVOLVE?

- Read and sign a consent form.
- Give a family and medical history.
- Answer a short environmental risk factor questionnaire.
- Take tests of memory, thinking, mood, and concentration.
- Complete a brief neurological examination.
- Give permission to review the medical records of the individual with memory and thinking problems.
- Provide a blood sample.

WHO CAN JOIN THE STUDY?

- Individuals with a diagnosis of frontotemporal degeneration
- Families that have 2 or more members with frontotemporal degeneration, both of whom are willing to participate in the study and any of their brothers and sisters who do not have a dementia disorder and are willing to participate
- The partners of individuals with frontotemporal degeneration or anyone over the age of 65 without memory problems as part of the study's non-dementia comparison group

THE RESEARCH TEAM

Physicians, psychologists, and human geneticists are all working together to find the genes that cause frontotemporal degeneration. We would like you to join our team!

