National Institute of Neurological Disorders and Stroke

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NINDS Frontotemporal Dementia Information Page

Synonym(s): Pick's Disease, Primary Progressive Aphasia, Semantic Dementia, Dementia - Semantic

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Clinical Trials

Natural History and Biomarkers of C9ORF72 ALS and FTD

The purpose of this study is to describe the natural history of disease in people who carry a repeat expansion mutation in the C9ORF72 gene.

More Information »
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What is Frontotemporal Dementia ?

Frontotemporal dementia (FTD) describes a clinical syndrome associated with shrinking of the frontal and temporal anterior lobes of the brain. Originally known as Pick's disease, the name and classification of FTD has been a topic of discussion for over a century. The current designation of the syndrome groups together Pick's disease, primary progressive aphasia, and semantic dementia as FTD. Some doctors propose adding corticobasal degeneration and progressive supranuclear palsy to FTD and calling the group Pick Complex. These designations will continue to be debated. As it is defined today, the symptoms of FTD fall into two clinical patterns that involve either (1) changes in behavior, or (2) problems with language. The first type features behavior that can be either impulsive (disinhibited) or bored and listless (apathetic) and includes inappropriate social behavior; lack of social tact; lack of empathy; distractability; loss of insight into the behaviors of oneself and others; an increased interest in sex; changes in food preferences; agitation or, conversely, blunted emotions; neglect of personal hygiene; repetitive or compulsive behavior, and decreased energy and motivation. The second type primarily features symptoms of language disturbance, including difficulty making or understanding speech, often in conjunction with the behavioral type's symptoms. Spatial skills and memory remain intact. There is a strong genetic component to the disease; FTD often runs in families.

Is there any treatment?

No treatment has been shown to slow the progression of FTD. Behavior modification may help control unacceptable or dangerous behaviors. Aggressive, agitated, or dangerous behaviors could require medication. Anti-depressants have been shown to improve some symptoms.

What is the prognosis?

The outcome for people with FTD is poor. The disease progresses steadily and often rapidly, ranging from less than 2 years in some individuals to more than 10 years in others. Eventually some individuals with FTD will need 24-hour care and monitoring at home or in an institutionalized care setting.

What research is being done?

The National Institute of Neurological Disorders and Stroke (NINDS), and other institutes of the National Institutes of Health (NIH), conduct research related to FTD in laboratories at the NIH, and also support additional research through grants to major medical institutions across the country.

NIH Patient Recruitment for Frontotemporal Dementia Clinical Trials

- At NIH Clinical Center
- Throughout the U.S. and Worldwide
- NINDS Clinical Trials

Organizations

Association for Frontotemporal Degeneration (AFTD)
Radnor Station Building #2 Suite 320
290 King of Prussia Road
Radnor, PA 19087
info@theaftd.org
http://www.theaftd.org; http://www.aftdkidsandteens.org
Tel: 267-514-7221 866-507-7222

National Institute on Aging (NIA)
National Institutes of Health, DHHS
31 Center Drive, Rm. 5C27 MSC 2292
Bethesda, MD 20892-2292
http://www.nia.nih.gov
Tel: 301-496-1752 800-222-2225 TTY: 800-222-4225

Related NINDS Publications and Information

- Dementia: Hope Through Research
  Information booklet about Alzheimer's disease, vascular dementia, and other types of dementia compiled by the National Institute of Neurological Disorders and Stroke (NINDS).

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