Searching for GENes in families with frontotemporal dementia, dementia with Lewy bodies and early onset alzheimer DEMentia

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The aim of the study is to identify genes that cause early onset Alzheimer dementia, dementia with Lewy bodies and frontotemporal dementia.

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Chromosomal abnormalities, gene alterations and gene variants
Study type	Observational invasive

Summary

ID

NL-OMON38398

Source
ToetsingOnline

Brief title
GENDEM

Condition

- Chromosomal abnormalities, gene alterations and gene variants
- Neurological disorders NEC

Synonym
Alzheimer disease, frontotemporal dementia

Research involving
Human

Sponsors and support

Primary sponsor: Vrije Universiteit Medisch Centrum

Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: Alzheimer dementia, dementia with Lewy bodies, frontotemporal dementia, genetics

Outcome measures

Primary outcome

identifying genes causing frontotemporal dementia, dementia with Lewy bodies

and early onset Alzheimer dementia

Secondary outcome

n/a

Study description

Background summary

Alzheimer disease (AD) and frontotemporal dementia (FTD) are the most common forms of presenile dementia (onset < 65 yrs). For both dementia types, 10 to 15 percent has a hereditary form with autosomal dominant mode of inheritance. Although some genes are known to cause autosomal dominant dementia, in several families with hereditary AD and FTD a causal gene defect has still to be found. Although dementia with Lewy bodies is in most cases sporadic, some patients have an autosomal dominant family history. No genes have been identified for autosomal dominant DLB. This suggests that more genes are involved in autosomal dominant dementia than we currently know of. The knowledge of other genes involved may expand the possibilities of genetic counselling and might contribute to the understanding of dementia.

Study objective

The aim of the study is to identify genes that cause early onset Alzheimer dementia, dementia with Lewy bodies and frontotemporal dementia.

Study design

Family based study:
An extensive family history will be taken. If the family is eligible for this

study, all affected persons and all 1st degree (presumed) unaffected relatives will be asked to participate. (Representatives of) affected participants will be asked for permission to request for their medical records. In unaffected participants, an medical history will be taken and, if applicable, permission to request for their medical records will be asked. Partners and children or other first-degree relatives of an presumed unaffected participant will be asked questions about the participant to confirm the unaffected state. DNA of all participants will be collected. Genetic anaylsis will take place at the section Medical Genomics by linkage or exome sequencing. Participants will not be informed on the results of questionnaires or of the outcome of the genetic analysis in their family.

Study burden and risks

The risks of participating in this study are negligible and the burden is minimal. Participants will be asked question about themselves and their relatives by phone, and will be requested to have blood drawn once. A visit at our hospital is not necessary, no physical examination will take place. Personal results will not be communicated to the participants.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

1.Families with (probable) autosomal dominant inheritance of frontotemporal dementia, dementia with Lewy bodies or early onset Alzheimer dementia.
- Families fitting autosomal dominant inheritance:
o Frontotemporal dementia or dementia with Lewy bodies in at least three persons in two consecutive generations, or
o Alzheimer dementia in at least three persons in two consecutive generations all with an onset below the age of 65 years.
- Families suggestive of autosomal dominant inheritance:
o Frontotemporal dementia or dementia with Lewy bodies in at least two persons, or
o Alzheimer dementia in at least three persons, 1st or 2nd degree related to each other, of whom at least one has an onset below the age of 65 years, or
o Alzheimer dementia in at least two persons, 1st or 2nd degree related to each other, with both an onset below the age of 65 years.;2. A sufficient understanding of the Dutch language and cognitive abilities to understand questions and procedures of participants or their (legal) representatives

Exclusion criteria

* Families in which a causal mutation has been identified
* Families that are known to be unwilling to participate in research
* Families in which no DNA of any affected person is or will be available

Study design

Design

Study type: Observational invasive

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Basic science

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	30-07-2011
Enrollment:	90
Type:	Actual

Ethics review

Approved WMO Date:	08-07-2011
Application type:	First submission
Review commission:	METC Amsterdam UMC
Approved WMO Date:	14-05-2012
Application type:	Amendment
Review commission:	METC Amsterdam UMC

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register	ID
CCMO	NL36113.029.11