Collaborative Genomic Studies of Tourette*s Disorder

Published: 20-09-2011
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The purpose of the study is to identify genes and genetic mechanisms that contribute to TD, chronic tics, and related clinical disorders including OCD and ADHD in individuals with these clinical phenotypes and their relatives.

Ethical review	Approved WMO
Status	Recruiting
Health condition type	Developmental disorders NEC
Study type	Observational invasive

Summary

ID

NL-OMON55561

Source
ToetsingOnline

Brief title
TIC Genetics

Condition

- Developmental disorders NEC

Synonym
Tourette's disorder; Tourettes

Research involving
Human

Sponsors and support

Primary sponsor: Accare
Source(s) of monetary or material Support: National Institute of Mental Health van de VS

Intervention

Keyword: ADHD, DNA biobank, genetics, Tourette's disorder

Outcome measures

Primary outcome

Presence of TD or other tic disorders (including chronic motor or vocal tic disorder, transient tic disorder, and tic disorder not otherwise specified).

Secondary outcome

Symptoms of OCD (including subclinical OCD and Obsessive-Compulsive personality disorder); symptoms of ADHD and trichotillomania.

Study description

Background summary

Tourette*s Disorder (TD) is a developmental neuropsychiatric syndrome characterized by persistent vocal and motor tics. While initially considered rare, the prevalence is now estimated to be 0.3-1%. Both as a result of potentially disabling symptoms and high rates of psychiatric co-morbidity, particularly with obsessive-compulsive disorder (OCD) and attention-deficit/hyperactivity disorder (ADHD), TD represents a significant public health concern. This protocol is part of an international collaborative group, entitled *Tourette International Collaborative Genetics (TIC Genetics)*. The DNA, cell lines, and clinical information will be stored at Rutgers University as part of the National Institutes of Mental Health (NIMH) Center for Collaborative Genetic Studies on Mental Disorders as an international resource.

Study objective

The purpose of the study is to identify genes and genetic mechanisms that contribute to TD, chronic tics, and related clinical disorders including OCD and ADHD in individuals with these clinical phenotypes and their relatives.

Study design

This is an international cross-sectional genetic biobanking multicenter study

in which seven US sites, fourteen European sites (including three recruiting sites from the Netherlands: UMCG, Yulius, de Bascule), and six South-Korean sites will perform a diagnostic assessment, followed by a single blood draw, aimed in 6300 individuals over a study period from 2011 to 2024, all being either parent-child trio*s or affected or unaffected members of pedigrees with three or more affected members with TD or chronic tics. European sites together will recruit at least 25 multiply affected extended families plus parent-child trio*s with a maximum of 2100 subjects over the study period 2011-2024.

Study burden and risks

The burden will be completion of a questionnaire (60 minutes), a single clinical evaluation (60 minutes), and a blood draw (15 minutes) through venipuncture. Risks will be negligible. Subjects will not receive any direct benefits from participation in the research. This research protocol includes the participation of minors. Tic disorders have a childhood onset, with tics usually starting around the age of 6.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adolescents (12-15 years)
Adolescents (16-17 years)
Adults (18-64 years)
Children (2-11 years)
Elderly (65 years and older)

Inclusion criteria

Either parent-child trios (i.e. affected person with Tourette's disorder plus his/her biological parents) or extended pedigrees, with a primary proband with Tourette's disorder and at least two relatives (up to the fourth degree) who are affected with Tourette's Disorder or chronic motor tic disorder.

Exclusion criteria

No informed consent or resistance of minors against blood sampling

Study design

Design

Study type: Observational invasive

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

Recruitment

NL

Recruitment status:	Recruiting
Start date (anticipated):	02-02-2012
Enrollment:	1002
Type:	Actual

Ethics review

Approved WMO Date:	20-09-2011
Application type:	First submission
Review commission:	METC Universitair Medisch Centrum Groningen (Groningen)
Approved WMO Date:	05-12-2012
Application type:	Amendment
Review commission:	METC Universitair Medisch Centrum Groningen (Groningen)
Approved WMO Date:	24-07-2014
Application type:	Amendment
Review commission:	METC Universitair Medisch Centrum Groningen (Groningen)
Not approved Date:	04-03-2016
Application type:	Amendment
Review commission:	METC Universitair Medisch Centrum Groningen (Groningen)
Approved WMO Date:	25-10-2017
Application type:	Amendment
Review commission:	METC Universitair Medisch Centrum Groningen (Groningen)
Approved WMO Date:	13-04-2022
Application type:	Amendment
Review commission:	METC Universitair Medisch Centrum Groningen (Groningen)

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	NL37812.042.11