Psychological consequences of PGD in families where one of the parents is a carrier of Huntington*s Disease

Published: 19-12-2014
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To gain insight (1) into psychological functioning of couples where one partner is carrier of HD and who have PGD child(ren); and (2) into the family interactions in these families.

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Neurological disorders congenital
Study type	Observational non invasive

Summary

ID

NL-OMON40909

Source
ToetsingOnline

Brief title
PGD in Huntington families

Condition

- Neurological disorders congenital

Synonym
Huntingtons chorea, Huntingtons disease

Research involving
Human

Sponsors and support

Primary sponsor: Klinische Genetica
Source(s) of monetary or material Support: ZONMW

Intervention

Keyword: Huntingtons disease, PGD, Preimplantation genetic diagnosis, Psychological aspects

Outcome measures

Primary outcome

Current psychological functioning of parents and their family

Secondary outcome

n.a.

Study description

Background summary

Huntington's disease (HD) is an autosomal dominant neurodegenerative adult onset disorder. HD has a significant impact on the whole family. Couples where one partner is a carrier of HD and who want are seeking to have children have several reproductive options to avoid passing on the HD gene to offspring, including preimplantation genetic diagnosis (PGD). PGD can provide direct testing of embryos obtained after in vitro fertilisation (IVF), and subsequently, if available, an unaffected embryo is selectively transferred into the uterus. On the one hand, there is broad societal and political support for PGD if one of the parents is a carrier of HD. On the other hand, there are moral and psychological questions with regard to current PGD-practice. These include concerns about the quality of life of PGD-children who grow up in families with serious genetic disorders. There is little data on psychological functioning of PGD/HD families, families in which one of the parents will have HD in the future, or in which the parent is already symptomatic.

Study objective

To gain insight (1) into psychological functioning of couples where one partner is carrier of HD and who have PGD child(ren); and (2) into the family interactions in these families.

Study design

Retrospective cohort-study by means of semi-structured interviews.

Study burden and risks

The study procedure consists of one interview, of which the adverse impact is expected to be limited. The researcher is a psychologist and is able to recognize signs of extreme stress and help the couple.

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

Parents who have one or more children by means of PGD and for whom (proven) Huntington*s disease in one of the parents was the indication for PGD .

Exclusion criteria

Severe cognitive deficiency and psychiatric disturbances. If these are a consequence of Huntingtons disease, the unaffected partner, if available, will be approached for the interview.

Study design

Design

Study type: Observational non invasive

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

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	26-03-2015
Enrollment:	48
Type:	Actual

Ethics review

Approved WMO

Date:	19-12-2014
Application type:	First submission
Review commission:	METC academisch ziekenhuis Maastricht/Universiteit Maastricht, METC azM/UM (Maastricht)

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	NL50498.068.14

Study results

Date completed:	03-01-2016
Actual enrolment:	18

Summary results
Trial is onging in other countries