# Evaluation of hand function in patients with Duchenne muscular dystrophy, including an additional pilot study with a newly designed glove. An explorative study.

Published: 29-06-2015 Last updated: 13-04-2024

To examine the natural disease course in the hands of persons with DMD and to explore relations between the level of body function/structures and the level of activities, according to the ICF model.

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

# Summary

### ID

NL-OMON41821

**Source** ToetsingOnline

**Brief title** Hand function in Duchenne.

## Condition

Neuromuscular disorders

**Synonym** Duchenne disease, Duchenne muscular dystrophy

#### Research involving

Human

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### **Sponsors and support**

**Primary sponsor:** Revalidatiegeneeskunde **Source(s) of monetary or material Support:** vanuit opleidingsgelden voor medisch specialist (revalidatiegeneeskunde)

### Intervention

Keyword: Activities, Disease course, Duchenne muscular dystrophy, Hand function

### **Outcome measures**

#### **Primary outcome**

The primary goal of this study is to examine the natural disease course in the hands of persons with DMD. We will evaluate two different levels of human functioning according to the International Classification of Functioning, Disability and Health (ICF) model; the dimension of body function and structures as well as the dimension of activities. To measure strength and function we will use the recently developed tools MyoPinch, MyoGrip and MOVIPLATE. To assess the presence of contractures we will measure range of motion using goniometry. To evaluate and describe activities we will use several instruments, including Brooke, MACS, PUL, Timed-TIHM and CUE. We will perform an additional pilot in 5 to 15 patients where we will measure hand kinematics with a recently designed glove (TU Twente).

#### Secondary outcome

Secondary goals of this study are to explore relations between these two levels, the possible difference between the dominant and non-dominant hand, and possible influence of posture and/or training or splints.

# **Study description**

#### **Background summary**

The distal muscles of the arm are the best-preserved muscle groups until the later disease stages in boys/men with Duchenne muscular dystrophy (DMD), as described in published literature. With the increased life expectancy it is of great importance to maintain as many abilities as possible to perform activities of daily living; to manipulate assistive devices and use a mobile phone for example. Not much is known about the natural disease course in the hands of persons with DMD and in particular the possible relations between the different levels of functioning according to the ICF model. In our explorative study we will search for potential relations between the level of body structures/functions and the level of activities. The results might influence and/or increase therapeutic options in the future.

#### **Study objective**

To examine the natural disease course in the hands of persons with DMD and to explore relations between the level of body function/structures and the level of activities, according to the ICF model.

#### Study design

An explorative study with a cross-sectional design.

#### Study burden and risks

Burden associated with participation will be limited, since measurements are non-invasive. Patients may experience some fatigue and/or muscle pain. Since there is no training in our study we believe this possibility is very small.

# Contacts

Public Selecteer

Stieltjesstraat 95 Nijmegen 6511AJ NL Scientific Selecteer Stieltjesstraat 95 Nijmegen 6511AJ NL

# **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**

A DNA-established diagnosis of DMD Informed consent

### **Exclusion criteria**

Presence of other disabling disease(s) with (major) influence on strength, mobility or activities, especially concerning the hand. Unable to cooperate with or understand testing

# Study design

### Design

Study type: Observational non invasiveMasking:Open (masking not used)Control:Uncontrolled

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Primary purpose:

Other

### Recruitment

NL	
Recruitment status:	Recruitment stopped
Start date (anticipated):	26-10-2015
Enrollment:	50
Туре:	Actual

# **Ethics review**

Approved WMO	
Date:	29-06-2015
Application type:	First submission
Review commission:	CMO regio Arnhem-Nijmegen (Nijmegen)

# **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 CCMO **ID** NL52246.091.15