

Group medical appointments for neuromuscular patients

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Patients who attend a shared medical appointment will have better self efficacy, are more satisfied with their care and have a better quality of life than patients who attend the usual one on one outpatient appointment with their doctor. Costs...

Ethische beoordeling	Positief advies
Status	Werving nog niet gestart
Type aandoening	-
Onderzoekstype	Interventie onderzoek

Samenvatting

ID

NL-OMON28911

Bron

Nationaal Trial Register

Verkorte titel

GMA, GMC

Aandoening

The following specific chronic neuromuscular diseases are selected:

1. Myotonic dystrophy = myotone dystrofie
2. facioscapulohumeral dystrophy,
3. chronic progressive external ophthalmoplegia,
4. oculopharyngeal muscular dystrophy,
5. inclusion body myositis,
6. McArdle's disease

Ondersteuning

Primaire sponsor: Universitair Medisch Centrum Nijmegen Radboud

Overige ondersteuning: ZONMW

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

- Quality of life

Toelichting onderzoek

Achtergrond van het onderzoek

To compare group medical appointments (group visits) with conventional one to one appointments for patients with a chronic neuromuscular disease in terms of quality of life, self efficacy, satisfaction, use of care and costs. Group medical appointments are 2-hour physician appointments in the company of other patients with the same neuromuscular disease.

Doel van het onderzoek

Patients who attend a shared medical appointment will have better self efficacy, are more satisfied with their care and have a better quality of life than patients who attend the usual one on one outpatient appointment with their doctor. Costs maybe lower because of the higher volume of patients that can be seen during a shared medical appointment.

Onderzoeksopzet

baseline, 1,3 and 6 months

Onderzoeksproduct en/of interventie

Intervention group:

Group medical appointment during a 2 hour session at the outpatient clinic of the department of neurology

Control group:

usual care (one on one visit at the outpatient clinic of the department of neurology)

Contactpersonen

Publiek

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Wetenschappelijk

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Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

Follow up patients > 18 year, with the following specific chronic neuromuscular diseases are selected:

1. Myotonic dystrophy = myotone dystrofie
2. Facioscapulohumeral muscular dystrophy (FSHD)
3. Chronic progressive external ophthalmoplegia (CPEO)
4. Oculopharyngeal muscular dystrophy (OPMD)
5. Inclusion body myositis (IBM)
6. McArdles' disease
7. Myositis: Dermamyositis and Polymyositis
8. Polyneuropathy: CMT1(a) & HMSN1

9. Non-dystrophic myotonias: chloride and sodium channelopathies.

Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

1. Hearing impairment
2. Not able to communicate well in Dutch language

Onderzoeksopzet

Opzet

Type:	Interventie onderzoek
Onderzoeksmodel:	Parallel
Toewijzing:	Gerandomiseerd

Controle: Geneesmiddel

Deelname

Nederland	
Status:	Werving nog niet gestart
(Verwachte) startdatum:	01-07-2008
Aantal proefpersonen:	270
Type:	Verwachte startdatum

Ethische beoordeling

Positief advies	
Datum:	18-08-2008
Soort:	Eerste indiening

Registraties

Opgevolgd door onderstaande (mogelijk meer actuele) registratie

Geen registraties gevonden.

Andere (mogelijk minder actuele) registraties in dit register

Geen registraties gevonden.

In overige registers

Register	ID
NTR-new	NL1352
NTR-old	NTR1412
Ander register	CMO : 026550
ISRCTN	ISRCTN wordt niet meer aangevraagd

Resultaten

Samenvatting resultaten

N/A