

Physical Therapy (PT) in Duchenne

Standards of Care in the Netherlands

Dr Menno van der Holst

Pediatric physical therapist / Researcher



Dr Erik Niks, Pediatric Neurologist

Dr Imelda de Groot, Pediatric Physiatrist

The DMD SOC Physical Therapy workgroup



DISCLOSURE

- No potential conflicts of interest to report
- 1 day work on Grant spieren voor spieren
- Lead PT LUMC for trials Biomarin, Roche, Italfarmaco, Santhera, Eli Lilly

Physical Therapists

n=28.200¹

- Regular
- Pediatric
- Manual
- Etc.



¹ tentative number, CBS statline 2016, last updated April 2018, www.staatvonz.nl,

Situation in the Netherlands



← Academic Centers (n=8)¹ mainly diagnostics, follow-up (outcome measures) and treatment advise



← Hospitals (n=105)¹ mainly follow-up, possibly treatment



Rehabilitation Centers (n=37)² →
Follow-up (outcome measures)
and treatment

Private Practices (n=7778)³ →
Mainly treatment



¹ <https://www.nvz-ziekenhuizen.nl>

² Revalidatie Nederland

³ www.zorgkaartnederland.nl

PT DMD SOC workgroup

Academic Centers (n=8)

- Dr Menno van der Holst, chair (Leiden UMC)
- Dr Merel Jansen (Radboud UMC)
- Maaïke Pelsma (Radboud UMC)
- Bart Bartels / Danny van der Woude (Utrecht UMC)
- Dyta Teule (Utrecht UMC)
- Dr Imelda de Groot (pediatric physiatrist Radboud UMC)
- Dr Erik Niks (pediatric neurologist Leiden UMC)

Hospitals (n=0)

Rehabilitation Centers (n=3)

- Saskia van Exter (RRC Leiden)
- Anton Comuth (Adelante Maastricht)
- Karel Pelger (ATLENT Tolbrug, Den Bosch)

Private Practices (n=0)

Patient organisations (n=2)

- Klaartje Spijkers (DPP)
- Charlotte van Esch (Spierziekten NL)



Procedure

Listing of all Physical therapy items in SOC (May/June)

Categorising of PT items (May/June)

Survey of consideration to SOC PT items in workgroup (July/August)

Teleconference on agreement and consensus (September 3rd)



- Advise on care items n=36
 - Assistive devices, sports, energy conservation, education etc.
- Assessment categories n=7
 - ROM, strength, muscle extensibility, posture, function, QoL participation
- Physical therapy interventions n=24
 - Exercise, Stretching, Hydrotherapy, Motor skills etc.
- Splinting, orthotics, serial casting n=5
 - AFO's night, AFO's day, KAFO's, serial casting, hand splints.

Consideration of PT items was questioned

- Do you advise on/apply the following consideration item:
 - Always – Sometimes – Never

Results

- All members completed the questionnaire
- Answers were dependent on:
 - Work location (academic, hospital, rehabilitation, private practice)
 - Population

- All items were considered important
- PT's have an important signalling function
- Details on indication not always clear
- Details on methodology not always clear
- Applicability dependant on work location
(academic, hospital, rehabilitation, private practice)



- Care items discussion points
 - Standing, lung volume recruitment, education of teachers/school personnel (gymnastics)
- Assessment categories discussion points
 - Quality of Life (how to measure)
- Physical therapy interventions discussion points
 - Stretching, exercising
- Splinting, orthotics, serial casting discussion points
 - (K)AFO's, serial casting.

- Assessments Mostly once a year
 - Collaboration between centers (academic and rehabilitation) to assess every 6 months
 - Is every 4-6 months always necessary?
- Assessments in line with SOC
 - Duchenne Center Netherlands outcome measure protocol
 - Implemented in all academic centers
 - Implement in rehabilitation centers and/or private practices?

Due to time and staff issues protocol not always fully used

How to proceed?

- To implement the SOC
 - Input from pt's in all practices needed (academic, rehabilitation, private practice etc.)
 - Make sure every item is considered (if needed)
 - Must be clear what, when and how
 - Gain more knowledge/evidence on natural history (parelsnoer)



How to proceed?

National guideline on physical therapy in DMD

- Based on the international standards of care
- Based on evidence
- Based on best practice
- Based on professional experience
- Based on the patients perspective

Duchenne Center the Netherlands in collaboration with the rehabilitation and physical therapy societies and the Duchenne Parent Project

GUIDELINE

