

WDO MEMBER MEETING 2023

EMERGENCIES IN DMD



WAT PATIËNTENORGANISATIES KUNNEN DOEN

Informatie beschikbaar maken voor families en vrienden

- Video (onderdeel van de Duchenne Care Video's)
- Spoedkaartje (meerdere talen, let op vakanties)
- Toegang tot relevante informatie voor (para)medici
- App om je medische gegevens bij je te hebben
(Duchenne Data platform)

Emergencies



Keywords: Emergency room, emergency card, internet, dizziness, steroids, measurement of Carbondioxide, team, FES, fat embolism Syndrom, chestpain



WAT PATIËNTENORGANISATIES KUNNEN DOEN

Informatie geven over hoe je emergencies kunt voorkomen:

- Vaccinaties op orde (ook voor vakanties)
- Altijd gordel vast in rolstoel
- Schoeisel, gladde vloer
- Niet vasten
- Stay hydrated
- Ambu bag bij de hand



WAT PATIËNTENORGANISATIES KUNNEN DOEN

Informatie hoe je je kunt voorbereiden

- Saturatie/hartslag metertje (& thermometer)
- Lijstje wat je mee moet nemen in spoedgevallen
- Lijstje telefoonnummers
- Medische gegevens (incl medicijnlijstje) bij de hand
- Dextro pur of glucose gel in huis



WAT PATIËNTENORGANISATIES KUNNEN DOEN

Informatie hoe je kunt voorbereiden (2)

- Emergency oefening doen
- Waar is (ook op vakantie) beste ziekenhuis
waar je naartoe kunt?
- Voorbereiden op stroomstoring (generator?)



WAT PATIËNTENORGANISATIES KUNNEN STIMULEREN

Hoe kunnen we de situatie in ziekenhuizen verbeteren

- Waar kun je een rode vlag plaatsen 🚩 om te waarschuwen dat dit een Duchenne/Becker patient is
- Benoem de risico's en waar informatie te vinden is:
 - Steroiden: stress dosis
 - Botbreuken: Vetembolie of Fat Embolism Syndrome (FES)
 - Ademhaling: waarschuwing voor toedienen zuurstof zonder CO₂ goed in kaart te brengen
 - Vasten
 - Afwijkende bloedwaarden
 - Anesthesie risico's

WAT PATIËNTENORGANISATIES KUNNEN STIMULEREN

Hoe kunnen we de situatie verbeteren

- Bereikbaarheid
- Communicatie tussen verschillende teams
- Juiste informatie op de juiste plek
- Publicatie Nederlandstalig tijdschrift? NTvG?

Primary Care and Emergency Department Management of the Patient With Duchenne Muscular Dystrophy

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abstract

Primary care providers (PCPs) are usually the first point of contact with the health care system for patients with Duchenne muscular dystrophy (DMD), and patients often present to emergency departments in which providers have little experience in dealing with this condition. With this article, we give primary care and emergency medicine providers a background in the common issues that affect people with DMD. By acquiring some specialized knowledge about the multisystem medical complications of DMD and by applying general principles of primary care, such as timely immunization, anticipatory safety counseling, behavioral screening, and routine nutritional and developmental assessments, the PCP can be a valued and effective medical provider to patients with DMD. The PCP can provide access to and effective coordination among the patient's specialty caregivers. Moreover, the PCP can become a trusted advisor to the patient and his family about important medical decisions, as well as issues in the psychosocial, behavioral, and educational domains. This article also contains a "pocket guide" used to assess and manage common urgent medical problems that cause patients with DMD to seek care in the emergency department. With the background information discussed in this article, both PCPs and emergency medicine physicians can skillfully care for patients with DMD in their respective settings, optimizing patient outcomes.

THE MEDICAL HOME

Primary care providers (PCPs) are usually the first point of contact with the health care system for patients with Duchenne muscular dystrophy (DMD). Depending on age, patient choice, and local circumstances, PCPs are those physicians or nurse practitioners in the fields of pediatrics, family medicine, or internal medicine who are engaged in providing a "medical home" to their patients. The primary care medical home (PCMH) is defined as a "model or philosophy of primary care that

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The guidelines or recommendations in this article are not American Academy of Pediatrics policy and publication herein does not imply endorsement.

Drs Noritz and Naprawa served as chairpersons for the Duchenne Muscular Dystrophy Care Considerations Primary Care and Emergency Department Management Working Group, as convened by the Centers for Disease Control and Prevention, and drafted the initial manuscript; Dr Apkon, Ms Kinnett, Dr Racca, Ms Vroom, and Dr Birnkrant served on the Duchenne Muscular Dystrophy Care Considerations Primary Care and Emergency Department Management Working Group, as convened by the Centers for Disease Control and Prevention, and contributed to the development of corresponding recommendations; and all authors reviewed and revised the manuscript, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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