



Accredited Duchenne Centers Program

Screening criteria - children (aged 0-18 years)

Centers that apply for accreditation for children and meet the screening criteria can be scheduled for a visitation with a group of experienced professionals and a patient representative. Criteria for children are in agreement with the latest care considerations and/or expert opinions.^{1,2,3}

Screening criteria for children are¹:

Organization of health care

- The number of children with DMD treated is in relation to the care region
- Pediatric DMD care is provided by a multidisciplinary team (patients have access: neuromuscular specialist (rehabilitation physician and/or neurologist), cardiologist, respiratory physician, physiotherapist, occupational therapist, speech and language therapist, dietitian, (clinical neuro)psychologist)
- Multidisciplinary pediatric DMD care may be delivered either by one center, or shared with other locations; however, the applying center is responsible for the care plan, communication, documentation and collaboration

Diagnosis

- Genetic testing is used to confirm the diagnosis

Carriers and genetic counseling

- Family members at risk receive genetic counseling
- Female carriers have access to cardiac check-up
- Symptomatic female carriers receive regular physical assessment
- Symptomatic female carriers receive regular cardiac check up

Neuromuscular management

- Patients are advised to use corticosteroids

¹ Criteria described are the minimum criteria. The multidisciplinary team can recommend more frequent follow-ups if needed.

Rehabilitation management

- Comprehensive multidisciplinary rehabilitation assessments are done at least once every 6 months in line with the disease stage (can be in shared care; assessments are done at least once per year in the main center)

Endocrine management

- Assessment of height is done at least once every 6 months
- Family education on adrenal crisis and stress dose steroid prescription if children are on glucocorticoids

Gastrointestinal and nutritional management

- Assessment by a nutrition dietitian at least annually
- Assessment of body weight at least annually
- Preventing both overweight and underweight
- Annual assessment of the level of vitamin D
- Annual assessment of dietary calcium intake

Respiratory management

- Respiratory assessments are initiated in the ambulatory stage
- Respiratory function is measured at least once every six months in non-ambulatory children
- Children with DMD receive lung volume recruitment if needed
- Children with DMD receive nocturnal ventilation if needed
- Children with DMD are advised to receive up to date immunization according to the national guidelines (influenza vaccines, covid and pneumococcal vaccines)

Cardiac management

- Cardiac function is assessed at least once per year in children with DMD from diagnosis (more often if needed)
- Cardiac function is assessed with an echocardiogram and/or electrocardiogram
- Children with DMD receive a cMRI once every 2-5 years or on clinical indication
- ACE inhibitors or angiotensin receptor blockers are initiated by age 10 years
- Standard heart failure interventions are provided with deterioration of systolic function

Bone health management

- Lateral spine X-rays are performed at least once every 1-2 years in children with DMD on glucocorticosteroids to detect early manifestations of bone fragility
- Lateral spine X-rays are performed at least once every 2-3 years in children with DMD not on glucocorticosteroids to detect early manifestations of bone fragility

Orthopedic management

- Joint range of motion is assessed at least once every six months
- Annual visual monitoring for scoliosis in ambulant children with DMD
- Visual monitoring for scoliosis at least once every six months in non-ambulatory children with DMD

Psychosocial management

- A mental health clinician (such as a psychologist or social worker) is part of the multidisciplinary team
- Mental health and quality of life of children with DMD and their families are assessed at every clinic
- Children with DMD and their families receive ongoing mental support
- Neuropsychological evaluations and interventions for learning, emotional and behavioral problems are provided

Transition

- Active approach to transition
- Engagement in (optimistic) discussion about future

Primary care

- The primary care provider is part of the care team and works in partnership with the multidisciplinary team

Perioperative and anesthetic care

- There is always a pre-anesthetic assessment which includes assessments of 1) airway (mouth opening), 2) cardiac status (echo/cMRI) and 3) respiratory status

References

- 1) Birnkrant et al. (2018). Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. *Lancet Neurology*; 17(3):251-267.
- 2) Birnkrant et al. (2018). Diagnosis and management of Duchenne muscular dystrophy, part 2: respiratory, cardiac, bone health, and orthopaedic management. *Lancet Neurology*; 17(4):347-361.
- 3) Birnkrant et al. (2018). Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across lifespan. *Lancet Neurology*; 17(5): 445-455.