

Clinical networks

Ensuring best care for those living with muscle disease through audit, review and standardisation of clinical processes.

The NorthStar Project for Duchenne muscular dystrophy



The NorthStar Project was set up in 2003 to help drive improvements in services and set national standards of care for children living with Duchenne muscular dystrophy (DMD).

Download the [NorthStar ambulatory assessment form](#).

The project aims to:

- **Provide best support to patients** - by agreeing protocols for assessment and best practice treatment options.
- **Assist clinicians working with muscle disease** - by developing a national clinical network and providing a discussion forum to promote best patient care.
- **Standardise and optimise steroid therapy**- in ambulant children with DMD throughout the UK.
- **Ensure a standard assessment protocol**- for newly diagnosed children and those due to start corticosteroid treatment.

Key developments of the project so far are launches of:

- **A national NorthStar Database in October 2006**- to gather information on disease activity in a large group of patients with DMD.
- **A UK wide NorthStar Clinical Network**- which includes 21 consultants, 17 Physiotherapists and allied health professionals from many specialist paediatric neuromuscular centres.

Following a lengthy process of consensus and review, the project has also produced:

- **A Statement** on the role of glucocorticoid corticosteroids in Duchenne muscular dystrophy.
- **A nationally standardised NorthStar Assessment Protocol**- for long-term monitoring of ambulant patients with Duchenne muscular dystrophy. Medical and physiotherapy assessment systems have been produced. Tests include assessment of functional abilities, muscle strength and pulmonary function.

The North Star Clinical Network consists of specialist paediatric neuromuscular centres from across the UK:

- **Clinical Lead:** Dr A Manzur, Dubowitz Neuromuscular Centre, Great Ormond Street Hospital, London, UK.
- **Academic Lead:** Professor F Muntoni, Dubowitz Neuromuscular Centre, Great Ormond Street Hospital, London, UK.
- **Project coordinator:** Elaine Scott, Muscular Dystrophy Campaign, London UK.