

A follow up plan for Duchenne muscular dystrophy based upon the Scandinavian protocol

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We have made a plan for the follow up of boys with Duchenne muscular Dystrophy (DMD).

Such a plan can secure the follow up of boys with DMD and give an overview of the needs in advance both for the families, the local community and hospital services. This can be used as a base for calculating the resources necessary for this lifelong follow up of DMD.

The plan is based on the 2nd version of the Scandinavian protocol for follow up of boys with DMD.

The plan has been based on several different occupations from the habilitation department.

The plan consist of a general part with description of diagnosis, development and major problems in different age groups and a part with division of responsibilities between the local community, the habilitation department, and other parts of the hospital system to cover the different needs for the DMD boys.

The plan is divided into: 1. from diagnosis to 6 years of age, 2. from 6 years of age to 12 years of age, 3 from 12 years of age to 18 years of age, and 4. above 18 years of age.

The period from diagnosis to 6 years is dominated by diagnosis, information both to the family and the employee in the local community, starting responsibility group around the DMD boy and his familial, sharing of responsibilities between the local community and the habilitation department, social and physiotherapy measurements and medical implications of the diagnosis The period from 6 to 12 years is dominated by loss of muscle power and ambulation, medical and physiotherapy measurements, cognitive evaluations and advice to the school. Social interaction is important to secure the DMD boy and his family.

The period from 12 to 18 years of age are dominated by increase medical problems around respiratory and cardiac functions, increasing scoliosis and preparing the DMD boy for an independent adult life. The DMD man will most likely live to about between 30

and 40 years of age. The period after 18 years will be dominated by possibility for an independent life, work, social life and necessary medical, social and physiotherapy measurements.

Keywords: Duchenne muscular dystrophy, follow up plan, primary care, and hospital services.