Abstract
In Sweden there are 250 boys/men with Duchenne muscular dystrophy (DMD). DMD leads to severe muscle weakness and disability and to early death. Population-based studies are important not only for monitoring the effects of any preventive measures such as genetic counseling, as well as for planning hospital resources and rehabilitation services. It also gives valuable information for further research studies. The aim of this project was to study the age and cause of death in a population-based cohort of patients with DMD from Sweden. With the ventilator treatment given today we believe that more patients die in heart related death instead of pulmonary related death.

We ordered information from The Death Index from The National Board of Health and Welfare and received information for all persons who died in Sweden between 2000-2010 and were diagnosed with the code G71.0. These are the diagnostic codes for primary muscle diseases such as Duchenne or Becker muscular dystrophy (1). We received information about 303 individuals. According to The National Board of Health and Welfare there were 69 persons with DMD. We screened 16 patients, who were from Västra Götaland through their medical journals. Among them we found one who didn't have the correct diagnosis. Therefore, we assume there are more patients from other districts who also have the wrong diagnosis. Altogether there were 68 persons in the study. We found four persons who didn't match the criteria of DMD just looking at The Death Index, they died at age 72, 62, 57 and 52 years, respectively. We assumed that these individuals had been wrongly diagnosed. We didn't have resources to look into these men's medical journals, because they were from other districts than Västra Götaland.

The results for the 64 patients most likely to have DMD shows that the patients died at an age of 10-46 years. The mean value was 25,1 years and the median was 25 years. There were 28 who died in a heart related death, 23 in a pulmonary related death, eight were the doctors just wrote "DMD" as the cause of death, two from pulmonary embolism, one who died of multiple organ failure, one of cerebral infarction and one from bleeding in the airways.

Cardiac and/or respiratory failure are still the main causes of death in DMD in Sweden. The
percentage distribution was however different from other studies (2), the heart related death was more common in this study. The age of death reported is similar to that reported in recent studies from other countries.

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