

Rare disease costs millions to society each year

July 3 2014, by Claes Keisu

In the first study of its kind, researchers at Karolinska Institutet and Newcastle University in the UK have estimated the economic burden of Duchene muscular dystrophy (DMD) to the public healthcare, affected households and society as a whole. According to research published in the July 2 issue of *Neurology*, the medical journal of the American Academy of Neurology, a typical DMD-patient annually costs society up to SEK 800,000, resulting in a total burden of SEK 480 million for the DMD population in Sweden.

DMD affects one in 3,500 new-born boys every year. The fatal condition is characterized by progressive muscle weakening caused by a faulty gene. Children with DMD lose their ability to walk independently and become reliant on wheelchairs for mobility usually in their early teens and many patients experience serious respiratory, orthopaedic, and cardiac complications following the aggressive disease development. Life expectancy is around 30 years.

The current study includes 770 patients from Germany, Italy, the UK and the US, who were asked to complete a questionnaire along with their primary caregiver. The results show that the per-patient annual direct cost of illness (SEK 160,000 – 360,000) in all these countries was seven to sixteen times higher than the average health expenditure. The figures include physician visits, clinical tests and assessments, drugs, and medical devices and aids, as well as [costs](#) associated with informal caregiving during leisure time. Other factors, such as [indirect costs](#) due to reduced working hours and reduction in quality of life, were also

calculated. Costs borne by each affected household were estimated at between SEK 400,000 and 500,000 annually, including out-of-pockets payments for healthcare services and drugs, loss of income, and reduction in quality of life.

The team behind the findings point out that rare diseases such as DMD often are underfunded, and that the [economic burden](#) to society are hidden because costs in many countries are carried by the family. Society's reluctance to invest in the development of treatments, clinics and specialist healthcare for people with DMD is another problem, according to the researchers.

More information: "The Burden of Duchenne Muscular Dystrophy: An International, Cross-Sectional Study", Erik Landfeldt, Peter Lindgren, Christopher F. Bell, Claude Schmitt, Michela Guglieri, Volker Straub, Hanns Lochmüller, Katharine Bushby. *Neurology* online July 2, 2014, [DOI: 10.1212/WNL.0000000000000669](https://doi.org/10.1212/WNL.0000000000000669)

Provided by Karolinska Institutet

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