Media Release

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Study reveals MD affects someone's wellbeing at twice the rate of cancer

"New research has revealed that compared to other health conditions, for a person with MD, more than two disability adjusted life years (DALYs) are lost each year, indicating a substantial loss of wellbeing [*graph below*]," said Muscular Dystrophy Australia's Executive Director, Boris M Struk.

The research has been published in the new report 'Economic study of muscular dystrophy', produced by *Deloitte Access* and funded by MDA, which is an in-depth look into the financial cost of MD on both individual families and the Australian economy.

"The 'Comparison of case burden' graph represents the poor quality of life a person with MD has compared to other major diseases such as cancer, which has a rate of one disability adjusted life year (DALY) lost each year. The reason why this is so, is because the total quantitative figure is reached taking into account a person's loss of quality of life due to their disability and also their premature death rate," said Mr Struk.

"Muscular Dystrophy is unique in that it has high rates for both of these factors, meaning people with MD may have both a restricted daily life due to the forced use of a wheelchair and muscle-wasting but in addition to this, may also have a shortened expected lifespan of 20-30 years of age."

"The reason MD has twice the level of adjusted life years (DALYs) lost each year compared to such a prevalent disease such as cancer, is that unlike most forms of MD a person can lead a completely condition-free life up until their diagnosis, sometimes not evening realising they are carrying the disease. Also, in some cases diagnosis can be obtained very late in life."

"For people with MD, such as the paediatric form Duchenne MD, diagnosis is between the ages of 2 and 4-years-old and for many they would require the permanent use of electric wheelchair by their teens and have a life expectancy of between 20 and 30 years," said Mr Struk.

Some of the other standout facts that we revealed in the new report are:

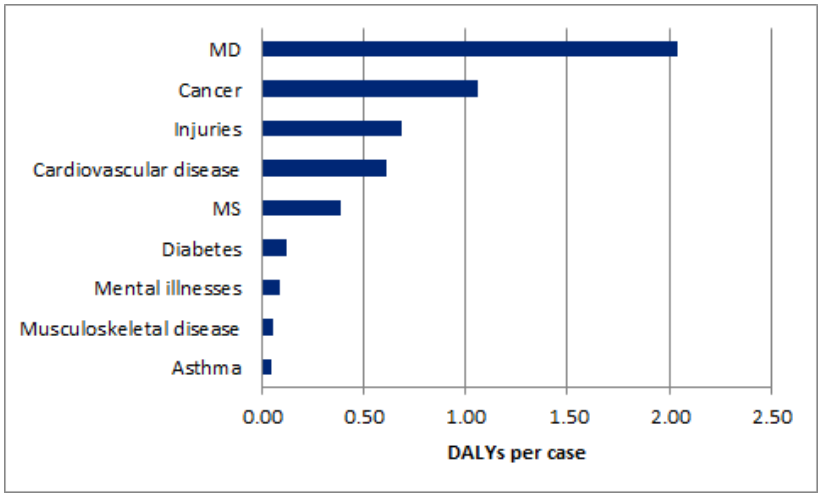
- "…The majority (two thirds) of people with MD fall within the lowest 40% of income groups – more than 70% of males and 60% of females with MD have a total cash income of less than $450 per week. This is less than the minimum wage per week in 2013 (Fair Work Ombudsman, 2013)." *('Economic Study of Muscular Dystrophy': Page v)*

- "Access Economics (AE, 2007) estimated that the total economic costs to Australian society of MD were around $1.4 billion in 2005. Adjusting for population growth and price inflation, the total costs of MD was estimated to be more than $1.8 billion in 2012." *('Economic Study of Muscular Dystrophy': Page vi)*

- "The cost of lost earnings due to MD was estimated to be approximately $41.0 million in 2012." (*'Economic Study of Muscular Dystrophy':* Page 10)

- "… Raising a child with a disability can possibly cost up to two to three times more than raising a child without a disability." (*'Economic Study of Muscular Dystrophy':* Page 18)

Chart ii: Comparison of case burden, Australia, 2012



Source: 'Economic study of muscular dystrophy', 2013

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To arrange an interview with Boris M Struk (Muscular Dystrophy Australia Executive Director) or obtain a copy of the full report please contact:

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