

Action Duchenne joins healthcare professionals in opposing Health and Social Care Bill

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Charity claims proposals will seriously affect current standards of care for people with life threatening neuromuscular conditions

Action Duchenne (<http://www.actionduchenne.org>) has announced its opposition to the Health and Social Care Bill due to be debated by again by the House of Lords from 8th February.

The Health and Social Care Bill represents the biggest change to the NHS since its inception, at a time when public health services are facing additional financial challenges.

Action Duchenne claims that the proposed changes and loss of statutory responsibility for neuromuscular services by the Secretary of State for Health and Primary Care Trusts will result in a threat to services for complex, chronic health conditions like Duchenne Muscular Dystrophy. With no legal responsibility to provide the standards of care specified by the National Commissioning for Neuromuscular Conditions, patients with complex illnesses will not be given the continuity and range of care services required.

The charity also claims that the reform will increase competition and impact communication amongst GP providers, resulting in fragmented and delayed services. Treatment of chronic health conditions will also be affected as GPs review prescribing costly new drugs as they face increased pressure to make savings.

Many professional health organisations, including The British Medical Association, the Royal College of GPs, Royal College of Nursing, Royal College of Midwives and Chartered Society of Physiotherapy have already publicly opposed the bill, with leading industry journals such as HSJ, Nursing Times and BMJ .

Nick Catlin, CEO of Action Duchenne said, "We are calling for the Health and Social Care Bill to be dropped. We believe that it will worsen the current standards of care for people living with complex neuromuscular conditions, preventing the necessary integrated health and social care that complex conditions like Duchenne Muscular Dystrophy require.

"We have long campaigned for a national coordinated network of specialist centres that people can access, as well as a statutory body to ensure the recommended standards of care are provided.

Early diagnosis of neuromuscular conditions, referring to specialist centres and the ability to fund clinical trials are all vital to combat this life wasting disease. The new Bill is a recipe for delayed diagnosis and chaotic and disjointed care as the health service looks to reform service delivery and reduce costs."

Kathy Wedell, mother of a son with Duchenne, and Chair of Action Duchenne's National Advocacy Council said,

'Our GP has never had a patient with Duchenne before – when we were first worried about Isaac and I took him to the GP he said 'run around the park with him a bit more'. Isaac's care is provided by

the excellent well-co-ordinated NHS team based at the local children's hospital. I don't want our GP sending us to cut-price competitors, with eleven different specialists in maybe eleven different locations, with no guarantee of a team working together or any continuity over time, and those competitors would inevitably undermine the provision we've already got. The real cost of all this won't just be the extra millions wasted in emergency hospital admissions, it'll be the life of my son and thousands like him.'

Action Duchenne, is the only national UK charity focused on raising awareness and funding for Duchenne Muscular Dystrophy. Duchenne is a severe muscle wasting disease that effects mostly males and is 100% fatal. The charity aims to find treatments or a cure for Duchenne by funding research and clinical trials, campaigning to make sure that everyone has access to the best standard of medical care, providing up to date support to families living with Duchenne and also to run a specialist education programmes (one of which received National Lottery Award in 2011).

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Notes to Editors

About Action Duchenne

Established in 2001 Action Duchenne aims to support and promote innovative research into a cure and effective medicines for Duchenne/Becker Muscular Dystrophy. The charity, which is led by Duchenne families, aims to promote awareness of the condition, to improve care services, and provide access to a range of educational and support/development programmes for people living with Duchenne at every stage of the condition. This is achieved by working in partnership with government agencies, NHS and care organisations, other charities, academic, scientific and research groups, and biotech companies worldwide.

Action Duchenne has consulted 26 members of our National Advocacy Council that includes young people living with Duchenne, parents and family members. The Charity has audited over 20 UK muscle centres and received responses from leading neuromuscular consultants on the extent of current care provision for Duchenne (www.dmdcentres.org) The Charity has a representative on the SAB of MDEX the leading UK Research consortium for genetic medicines for Duchenne. RDUK

Action Duchenne is actively campaigning for best practice in care for Duchenne based on the publication of an international consensus document in Lancet Neurology in Jan/Feb 2010. The published article was the product of an extensive review by 84 international experts in Duchenne Muscular Dystrophy diagnosis and care, and was supported by the Centers for Disease Control (CDC) in the US. It provides an expert guide to recommendations on the multidisciplinary care that should be available to all individuals with Duchenne. Several Duchenne patient organisations including Action Duchenne and the TREAT-NMD network have helped to produce a 'Guide for Families', based on the original academic article, which is written in language accessible to all without a medical background.

Since 2003 Action Duchenne has provided £4m for research projects and partnerships. The charity has worked with the MDEX consortium, Department of Health, and the Medical Research Council to deliver new clinical trials for Duchenne drugs. In addition, it has been instrumental in developing projects with

biotech companies both in the UK and US including key projects with AVI Biopharma and Summit.

In 2005 Action Duchenne launched the DMD Patient Registry, a national database that holds gene information of people living with Duchenne that is used to speed up the recruitment of patients for clinical trials. For more information please visit: www.dmdregistry.org

In 2008 Action Duchenne launched the Include Duchenne project in partnership with Decipha. This programme addresses the learning and behaviour needs of those living with Duchenne. In 2011 Include Duchenne won the National Lottery Award for Best Education Project for Decipha. For more information please visit: www.decipha.org

Action Duchenne promotes social inclusion within the community for young men living with Duchenne through its Genius programme. For more information please visit: www.actionduchenne.org/geniusproject

In 2010 the National Advocacy Council was launched to spearhead the lobby for government funding for research into Duchenne and to improve access to Standards of Care. www.actionduchenne.org/NAC

Patrons of Action Duchenne include: actress Helena Bonham-Carter, cellist Julian Lloyd-Webber, journalist & broadcaster Martin Bashir and radio broadcaster & media trainer Susan Bookbinder. In addition, Richard Goodman, one of Great Britain's leading young athletes is an Ambassador for Action Duchenne.

For more information please visit: www.actionduchenne.org

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