

# Annual Action Duchenne lobby heads for Cathays Park and the Welsh Assembly on 17 July 2012

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Families and supporters call on AMs to support Action Duchenne (<http://www.actionduchenne.org>)'s Boys to Men campaign and adopt the 4 Point Plan to end serious under-funding for medical care, support and research for life wasting condition

Hundreds of boys living with Duchenne Muscular Dystrophy, their families and supporters will be heading for the Welsh Assembly on Tuesday 17th July 2012. Set as the date of its Welsh lobby, Action Duchenne supporters and families will be lobbying AMs to demand match funding for its ground breaking research programme, improved multidisciplinary medical care to be delivered via 9 Centres of Excellence throughout the UK with at least one in Wales, and access to specialist educational support and support for independent living. Action Duchenne is the leading UK charity dedicated to raising awareness and funds for research into treatments and finding a cure and providing support for families living with Duchenne.

Duchenne Muscular Dystrophy is a severe muscle wasting disease that affects mostly males and is 100% fatal. Sufferers are diagnosed usually by the age of five and without good medical intervention they rarely live beyond their late teens and twenties.

In their message, the families will call for support for National Commissioning and a multidisciplinary centre of excellence for healthcare in Wales (access to which could add as much as 10 to 15 years' life expectancy and improve the quality of life). They will also request allocated funding for high quality research, for all patients living with Duchenne to have access to a first genetic treatment in the next 3-5 years and for individual health and social care planning with personalised budgets to promote independent living.

Nick Catlin, Head of Research at Action Duchenne, said; "Twenty years ago there was little treatment for Duchenne, but advances in medicine, including current clinical trials as well as internationally agreed standards of care, make a longer lifespan and improved quality of life for all young men living with Duchenne a real possibility.

"We are now on the verge of bringing truly ground breaking genetic treatments for Duchenne to the market, it is a critical time to invest in research for treatments that will see the condition stabilised to enable our young people to live longer. There is no doubt that our campaigns and the tireless fundraising of our families and supporters have already made a difference, but without further funding and government support we cannot achieve our goal of providing personalised care and support into adulthood to improve the quality of life for those living with Duchenne."

In its Lobby briefing document the charity details its key requirements which include; improved healthcare across the UK with nine specialised centres of excellence including at least one each in Scotland, Wales and Northern Ireland that can deliver the range of services set out in the Agreed Standards of Care for Duchenne; a total of £5million match funding to support its five year SkipDuchenne research programme, that will ensure that patients have immediate access to personalised genetic treatment.

It also calls for access to specialist educational assessments and interventions, careers advice and support to enable independent living and social inclusion. Action Duchenne already works with Decipha to support young people at school with Duchenne through specialist assessments and learning programmes, winning the National Lottery Award Best Education Project in 2012 for its work.

Martin Bashir, Broadcaster and Patron of Action Duchenne, added; "We need to do what we can to encourage research, raise funds and support families who confront this condition with such bravery and resolve."

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Time table for the day – Tuesday 17th July

11.30-12.00 Meet outside front of Welsh Assembly and make way to  
Conference Room 21

12.00-12.15 Meeting AMs and refreshments

12.15-1.30 Speakers and Q&A

1.30-2.00 Press, socialising and networking

Speakers

- Vaughan Gething (Assembly Member)
- John Burke (Nurse and father of Seth, a boy with Duchenne Muscular Dystrophy living in Wales)
- Dr Louise Hartley (Consultant Paediatric Neurologist)
- Rachel Salmon (Neuromuscular Care Advisor Medical Biochemistry University Hospital of Wales)
- Sarah Harris (Neuromuscular Care Advisor for West Wales)
- John Kinge (Father of Ethan, a boy with Duchenne Muscular Dystrophy living in Wales)

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 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](http://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](http://www.decipha.org) (<http://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](http://www.actionduchenne.org/geniusproject) (<http://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](http://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](http://www.actionduchenne.org)

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