

Action Duchenne pays tribute to brave Stuart Wickison aged 23

Submitted by: PR Artistry Limited

Wednesday, 10 August 2011

Stuart Wickison lived with Duchenne muscular dystrophy and sadly took his own life on Tuesday 2nd August . Stuart was found in a lake in his wheelchair near to where he lived in Eastbourne, Sussex.

We all remember Stuart at Action Duchenne (<http://www.actionduchenne.org>) for his tireless campaigning to raise awareness of the effects of the severe muscle wasting disease that left him paralysed with very little muscle function. All of us at the Charity will miss his sparkling humour, sharp observations and of course his persuasive arguments for change. Stuart was a talented musician, artist and writer and he worked last year with other young people on the short film "Duchenne: The Invisible Generation". He inspired other young people living with Duchenne and gave them hope for the future.

Stuart lobbied the government as recently as June this year where he joined hundreds of others to bring to the Governments notice the lack of care provision and support for young people with Duchenne. Stuart also supported the Charity in aiming to provide new drugs and medicines to treat this genetic condition so that future generations of young people would not have to suffer the same disabling loss of muscle.

Stuart like other young men living with Duchenne required a great deal of expert medical support to ensure his heart function and breathing were constantly monitored and supported. He required 24/7 round the clock care.

Nick Catlin CEO at Action Duchenne stated: "It was a pleasure and great privilege to have met and worked with such an inspirational young man. Stuart was angry that young people like himself were never listened to but he always expressed himself eloquently and with dignity. He campaigned so that families and other young people would be able to get the medical care, psychosocial support and treatments for Duchenne by right and not by postcode lottery. His determination to fight for change will be sadly missed by us all."

-ends-

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

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. 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

For more information please visit: www.actionduchenne.org

Editors Contacts

Andreina West
PR Artistry Limited
Tel: 01491 639500
email: Andreina@pra-ltd.co.uk