

Charity Action Duchenne combines social networking with e-commerce for innovative new website

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Action Duchenne builds online interactive community to help and support families living with Duchenne Muscular Dystrophy

Action Duchenne, the Duchenne Muscular Dystrophy Charity, has launched its new website which combines the best in Web 2.0 technologies including social networking, wikipedia, blogging and micro-blogging. The new site www.actionduchenne.org also enables the charity to take donations from registered members and the general public. Users may also create their own sponsorable events with donations going directly to Action Duchenne.

Nick Catlin, CEO of Action Duchenne commented, "We set up Action Duchenne eight years ago to provide support and education for families affected by Duchenne Muscular Dystrophy, and to raise money to find a cure. While we are closer to finding that cure, there is still a way to go, and in the meantime families find the help and support offered by our Duchenne community very comforting." Nick continued "Our new website has been designed to provide that interactive community so that families living with Duchenne can communicate more freely, share information about fund raising events, find information, we have a whole library of articles and papers written by many eminent scientists and people can donate those all important funds to help us continue our working in finding a cure for this most cruel of conditions."

Duchenne Muscular Dystrophy affects 1 in 3,500 male births in the UK, and is the most common and severe type of muscular dystrophy - sufferers are diagnosed usually by the age of 5. Patients with DMD and Becker Muscular Dystrophy (BMD) are boys and young men who lack dystrophin, a protein that is critical to the structural stability of muscle fibres. Patients develop progressive muscle weakness. Duchenne affects all muscles including the heart and respiratory system leaving young people paralysed by late teens and many patients do not live past their twenties.

The new website provides a wealth of information about Duchenne, what causes it and the current treatments, about campaigns, education and inclusion programmes, fund raising events, blogs, conferences and news. As well as this registered users can set up their own Stop Wasting web page, post pictures, post their own news, network with friends, blog and micro-blog and generally interact in the same way as on sites like Facebook and Twitter. The site also includes a Donations facility and an online store for Duchenne and Stop Wasting merchandise.

Anton Faulconbridge, Director of Rantmedia who built the site said, "We are delighted to continue our relationship with Action Duchenne on this very exciting project. Our 'eCharity' platform, with its full social networking, wiki-knowledgebase, e-commerce shop and user events has given Action Duchenne a cutting edge website that provides visitors with a complete community in which to share, interact and

fund raise.”

Carl Tilson, aged 22, living with Duchenne and an active campaigner for the charity commented, “The new website is great. Social networking is the way forward and is an advantage when your mobility is severely restricted. It enables me to interact and keep in touch with my fellow soldiers in the Duchenne community.” Carl continued “Having such an interactive website will assist the charity making that much needed awareness worldwide and great awareness will then guide us into a new beginning, a fresh start and will finally lead us into victory against this monstrous disease”
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Notes to Editors:

About Action Duchenne

Action Duchenne (formally Parent Project UK) was set up by Duchenne families in 2001 to promote new research for a cure for Duchenne. The charity has a strong record in funding research and has to date funded 8 major projects costing over £1m and has lead the £1.6m DoH funding of the MDEX project. These projects have enabled much needed early work to be completed on exon skipping and other therapeutic approaches.

Action Duchenne holds an international conference every year to bring together researchers and families to exchange new research developments and provide a vital meeting venue for scientists.

In 2005 Action Duchenne launched the Duchenne Patient Registry, the first National Duchenne database that holds gene information of people living with Duchenne and can be used to speed up the recruitment of patients for clinical trials. www.dmdregistry.org

In 2006 Action Duchenne launched a comprehensive learning and behaviour toolkit for use by parents and education professionals.

For more information please visit: www.actionduchenne.org

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