

Father kayaks across the English Channel to raise funds to fight son's illness

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Holiday hobby turns into serious fund-raising mission for local man and his two friends

Father from Dibden Purlieu, Stuart Littler, is to kayak across the English channel with his two friends, Charlie Brett and Jon Turner to raise funds to find viable treatments for his son, Ben. Ben, who is 6 in September, was diagnosed with Duchenne Muscular Dystrophy in December 2009. Since then the family have been working with charity Action Duchenne (<http://www.actionduchenne.org>) to raise money to improve awareness and funds for this life limiting condition. The three friends are novice kayakers and have never attempted anything like this before. In the process they have already met their initial target of raising £5000, and are now aiming for £10,000, to be donated to Action Duchenne. The crossing is set to take place during week commencing 27 August, and will be dependent on tides and weather.

The idea to cross the channel was thought up by John, after they bought surf kayaks for fun. The team have now been lent sea kayaks which you sit in (rather than sit on) by Venture Kayaks, and have received free training and coaching from Liquid Logistics. Southampton Freight Services volunteered to collect the kayaks from Runcorn and deliver them free of charge. The three friends have undertaken long training paddles twice a week and have encountered various adventures along the way, including near misses with container ships, paddling under piers and practicing their capsize drills.

Stuart Littler said; "Our lives changed forever when our eldest son Ben was diagnosed with Duchenne Muscular Dystrophy. He is a cheeky, happy little boy with a wicked sense of humour. He is a wonderful son, big brother and friend. He copes so well with what life has dealt him and we are very proud. At the end of August three of us will be attempting to cross the English Channel in sea kayaks. This is no mean feat by any standard, especially as we are not experienced paddlers. However, the goal of raising a significant amount of money to help raise awareness of this life limiting condition and to find viable treatments will keep us going."

Duchenne Muscular Dystrophy affects one in 3,500 male births in the UK, and is the most common and severe form of muscular dystrophy. Sufferers are diagnosed, usually, by the age of five and rarely live past their twenties. Since being established in 2001, Action Duchenne has successfully campaigned to increase awareness of the disease to improve standards of care and has raised several million pounds to fund medical research and partnerships. Action Duchenne has recently donated over £160,000 to Royal Holloway to support a ground-breaking project to develop a process for delivering full length dystrophin, which effectively could provide a cure.

Kate Angus, Operations Manager at Action Duchenne said; "A great many families in the UK are affected by Duchenne, and many of them turn to Action Duchenne for advice and guidance. They also dream up amazing challenges, like this one, to help raise funds so that one day, in the not too distant future, we will have life changing treatments for Duchenne. A challenge like this one, to cross the Channel in kayaks, is a huge undertaking and certainly provides inspiration for others. We would like to offer huge thanks to Stuart, John and Charlie for their bravery and determination."

For more information about Stuart's, John's and Charlie's Kayak Challenge please visit:
www.englishchannelkayakchallenge.blogspot.com

For more information on Action Duchenne and Duchenne Muscular Dystrophy please visit:
www.actionduchenne.org.

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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 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 Sarepta (previously known as 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. Its Takin Charge project is a programme aimed at developing skills of adulthood

that will be additional to GCSEs covering areas such as IT and social media, self advocacy for medical care, workplace skills, skills for independent living including developing a social life, relationships and sexual health. 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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