



changing lives

Living North highlights a new project which aims at raising awareness about Duchenne Muscular Dystrophy, the most common fatal genetic condition affecting children, in the United Kingdom

'LIFE THRU A LENS' – LIVING WITH DUCHENNE MUSCULAR DYSTROPHY

This Innovative photography project aims to show what living life with Duchenne is like by those whose lives are affected.

Action Duchenne's Genius Project is a new project funded by V, the National Youth Volunteering Organisation. Entitled "Life Thru a Lens", photographing life with Duchenne, the project aims to show what living with Duchenne is like, told in photographs by those whose lives that are directly affected. Over a six week period, Jason Thompson, an experienced photographer based in Northumberland and known for his creative photography and distinctive style, will be working with young men and volunteers to create an exhibition of photographs planned to be staged this summer at the Houses of Parliament, Young Tate and other venues around the country.

The charity, Action Duchenne, is responsible for recruiting volunteers onto the project and workshops are planned around the UK for photographers and volunteers over the next six weeks.

Vici Richardson, Partnership Development Manager for Action Duchenne heads up the Genius project, set up in 2008. Vici has been working for Action Duchenne for over three years, having started as fundraising coordinator in 2005. Married to Gavin, Vici has two children, Zak (6) and Sian (2). Her eldest son, Zak was diagnosed with Duchenne at eighteen months old. "As a parent I am very aware of what the future holds, however, I have realistic hope and like all of us who work at Action Duchenne, am determined to do what I can."

"This is a very exciting project that aims to raise awareness of Duchenne and bring the condition to the public eye in a personal and visual way. We hope that the photographs will be a personal document of a time and a place of a misunderstood condition. It plays an important part of our fundraising to support new research for treatments of this devastating disease."

Duchenne Muscular Dystrophy affects 1 in every 3,500 boys and young men, and occasionally girls also. With 40,000 sufferers worldwide, awareness of DMD is very low. Duchenne affects the heart and respiratory system and many patients do not live past their twenties. It is the most common fatal genetic condition affecting children in the United Kingdom. Action Duchenne is the only national charity exclusively funding research for a cure for Duchenne. Action Duchenne also campaigns for better Standards of Care and runs specialist education programmes.

Work has already begun on the project and according to Jason, bringing some exciting results, "This is a very significant project that could really help to change attitudes towards Duchenne, and show a slice of real life perhaps never seen before by those untouched by the condition. The young photographers are all very excited – they've risen to the challenge and their imaginations have been captured. I think that the resulting work will be a tribute to their determination and positive attitudes – they're inspirational."

More information about the project is available on www.lifethrualems.org.

To know more about the Genius project and about opportunities to volunteer on behalf of Action Duchenne, contact Vici Richardson, Partnership Development Manager, on 07920723494, email: vici@actionduchenne.org or visit: www.actionduchenne.org

For more information about Jason Thompson and his work: www.sound-ideas.net