

## Dubowitz Neuromuscular Centre, Great Ormond Street Hospital

Muscle disease is a progressive condition that causes muscles to waste and weaken making it hard for those affected to do even the simplest tasks. It doesn't just affect the muscles in the arms and legs but the heart and respiratory muscles too.

At its most severe people are, literally, unable to move a muscle and will have a much shorter life expectancy. It is genetic and often inherited, but can also occur out of the blue, even if there is no history in the family.

**Funded by the Muscular Dystrophy Campaign, the neuromuscular service at Dubowitz is the largest paediatric muscle clinic in the UK. It sees over 2,000 children each year.**

It is a national specialist centre for diagnosis, care and research.

The team at the centre works with adult services to ensure a smooth transition of care.



*"People sometimes ask me what Daniel is going to be when he grows up... I don't care, I just want him to grow up."*

Linda (Daniel's mother)

*"Our aim is a world where children like Daniel live beyond their 20s – the team at Dubowitz is making enormous strides towards achieving that."*

Philip Butcher (CEO, Muscular Dystrophy Campaign)

*"After years of investment we now understand a huge amount about the causes and effects of many types of muscular dystrophy and can now focus our energies on possible treatments and cures once considered unobtainable."*

Prof. Martin Bobrow (MDC Chairman)



*"The Muscular Dystrophy Campaign-research at Dubowitz is vital to help families and children understand their conditions and plan for the future."*

Prof. Francesco Muntoni (Director, Dubowitz Neuromuscular Centre)

### Research and diagnosis

Using cutting edge techniques, the research team is developing new, more accurate and straightforward descriptions of disease progression. Underpinned by our research the Centre's expert medical staff offer the best in clear, family-focused diagnoses. Everything is done to help families and children through this difficult time.

*"Families like ours need the help of the professionals from the Muscular Dystrophy Campaign. They have helped ever since our son was first diagnosed, which was a very frightening time for us. To have someone take the time to sit calmly with us to talk it over was a real help."*

Jane (Toby's mother)

## Care and support

Combined with the services at Great Ormond Street Hospital in London, the centre offers a range of therapies and care essential to the well-being of the children.



*"We were told that our little girl had muscular dystrophy on her 4th birthday, which was a terrible shock. We knew nothing about the condition and were put in touch with Martin, our Regional Care Advisor."*

**Paul (Lucy's father)**

The Regional Care Advisor at the Centre, Martin, provides practical and emotional support including advice on equipment, home adaptations and preparing for adult life. His work is an essential aspect of the care services we provide.



*"I see at first hand the enormous difference that proper care can make. The children I help each day are amazing, they have such resilience."*

**Martin Chainani (with Ronak)**

## Our supporters

Each year we need to raise £200,000 in order to continue providing these specialist services.

Particular thanks go to The Q Trust fundraising committee which has raised substantial funds for the centre. Made up of friends and family of Quentin Crewe and Mark Reynolds, the committee hopes that the lives of these two extraordinary men will inspire other children and adults affected by muscle disease.



*"Families like ours benefit so much from the work made possible by Muscular Dystrophy Campaign's supporters."*

**Mark (Murray's father)**