

# Six Steps to Fight Muscle Disease



Local patients living with neuromuscular conditions and their families – backed by the Muscular Dystrophy Campaign – are calling on you, as a Parliamentary candidate, to join the fight against muscle disease.

If elected as a Member of Parliament on 6 May 2010, we are asking that you support the following six key pledges:

1

**If I am elected on the 6 May, I will join the All Party Parliamentary Group for Muscular Dystrophy.**

The All Party Parliamentary Group for Muscular Dystrophy brings together MPs and Peers from across the parties and meets at least four times a year, to raise awareness of muscular dystrophy and related neuromuscular conditions.

**Phillippa Farrant from Eastbourne is the mum of 18-year-old Daniel who has Duchenne muscular dystrophy. She said:**

*"Giving evidence to the APPG for Muscular Dystrophy gave me a chance to tell Parliamentarians about the reality of living with muscle disease. I call on every MP to join the APPG on behalf of families like mine."*



2

**If I am elected on the 6 May, I will meet with my regional Muscle Group to discuss gaps in local services.**

Muscle Groups have been established across the country – the Muscle Groups are a vehicle for patients, clinicians and health professionals to share experiences and campaign for improvements in local services.

**Karen Bayliss, from Selly Oak, is affected by facioscapulohumeral muscular dystrophy. She is a member of the West Midlands Muscle Group and said:**

*"Through the Muscle Group and campaigning for better services I feel much more positive about my condition and am proud to be helping to bring about huge improvements to neuromuscular services. We need local MPs to support us in the fight for better services."*



3

**If I am elected on the 6 May, I will meet with regional health bosses to discuss with them what action they are taking to improve specialist services for people living with muscle disease.**

In England, the ten NHS Specialised Commissioning Groups are responsible for planning and developing neuromuscular services, whilst similar bodies exist in Scotland, Wales and Northern Ireland.

**Andy Findlay from Derby is affected by facioscapulohumeral muscular dystrophy. He said:**

*"My MP has met with the key decision makers who can make a real difference for people like me who are living with muscle disease. If elected, will you do the same for your constituents?"*



4

If I am elected on the 6 May, I will support a new All Party Parliamentary Group for Young Disabled People.

Two hundred young disabled people have joined forces to form *Trailblazers* – the UK’s only campaigning network for young disabled people. The *Trailblazers* are calling on MPs to launch a new All Party Group focusing on independent living and quality of life for young disabled people.

**Laura Merry is a *Trailblazer* from Buckinghamshire:**

*“It’s high time a new All Party Parliamentary Group for young disabled people is launched. Too often our needs are overlooked – I want MPs to care as much about these issues as I do and an All Party Parliamentary Group is the perfect vehicle for change.”*



5

If I am elected on the 6 May, I will meet with my regional *Trailblazer* ambassador and work with them in the fight to improve access to local transport, education and leisure facilities.

The *Trailblazers* have published hard-hitting reports about access to transport, education and leisure facilities and are calling on service providers to ensure that people with mobility difficulties can access these essential services.

**Dave Gale is a *Trailblazer* from Carlisle:**

*“I met my MP at the launch of the Muscular Dystrophy Campaign’s *Trailblazers* network in July 2008. He’s helped me in my fight to improve services for people with muscular dystrophy by supporting our *Trailblazers*’ campaigns. All MPs can help in this way”*



6

If I am elected on the 6 May, I will work with the Muscular Dystrophy Campaign to ensure vital funding for potential new treatments is a high priority within the NHS.

There are an estimated 70,000 people living with rare and very rare forms of muscle disease across the UK. There are currently no cures. As research for new treatments and therapies develops, it is essential that the NHS ensures that these are available to patients living with muscle disease.

**Mark and Jane Field live in Droitwich and have a 12-year-old son, Murray, with Duchenne muscular dystrophy. They said:**

*“There are no cures for neuromuscular conditions – but we are getting closer than ever before. We need MPs to work with us to make sure that these new and potentially life-saving treatments will be made available by the NHS.”*



**Together we’re stronger**



Make sure you are signed up to the Muscular Dystrophy Campaign’s Manifesto for Muscle by sending your name, and prospective constituency in an email to [campaigns@muscular-dystrophy.org](mailto:campaigns@muscular-dystrophy.org) We will then publish your name on our website.

For more information about the Muscular Dystrophy Campaign please visit:

[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

For more information about *Trailblazers* please visit: [www.mdctrailblazers.org](http://www.mdctrailblazers.org)