Muscular Dystrophy UK

Fighting muscle-wasting conditions

Manifesto for Muscle

Seven steps to fight muscle-wasting conditions in England

If I am elected on 8 June:

1. I will back Muscular Dystrophy UK in calling for faster access to new drugs for muscle-wasting conditions.
2. I will work to ensure that, after Brexit, patients do not experience delays in accessing emerging treatments for muscle-wasting conditions, the UK continues to be the best place for science and innovation, and the UK maintains its key role in Europe-wide research collaboration.
3. I will support my constituents who have muscle-wasting conditions at meetings of the All Party Parliamentary Group for Muscular Dystrophy.
4. I will meet with people living with muscle-wasting conditions at Muscular Dystrophy UK's local peer support 'Muscle Group' meetings to discuss the improvements they need to local services.
5. I will meet with Muscular Dystrophy UK's Trailblazers (young campaigners network) in my local area to back their campaign for removing barriers to living independently.
6. I will work to promote greater understanding of muscle-wasting conditions among benefits assessment providers and the Department for Work and Pensions so that people with these rare and complex conditions access the benefits they are entitled to as quickly as possible.
7. I will work to make sure people with muscle-wasting conditions have access to the expert care, support and equipment they need, including specialist physiotherapy, emotional and psychological support, and respiratory support equipment such as cough assist machines.

Sign up today and join the fight against muscle-wasting conditions!

Get in touch with Jonathan Kingsley on
j.kingsley@musculardystrophyuk.org or call **020 7803 4839**

Faster access to treatments in England

A number of treatments are in clinical trial for muscle-wasting conditions, such as Duchenne muscular dystrophy and spinal muscular atrophy (SMA), and are at or reaching the point where they are being considered for approval by regulators. It is crucial that treatment assessments are completed as quickly as possible so that patients can get access to treatments without delay.

Exondys 51, for example, could treat individuals with Duchenne muscular dystrophy whose mutation is amenable to exon 51 skipping. It could preserve muscle function and effectively slow down the progression of the condition.

"Exondys 51 helps maintain muscle strength that enables Charlie to walk a little longer and to hug his family and of course it offers, hope! Hope, strength and love is what gets you through and what this approval has given us is just that. We will do anything we can to enable this drug to reach all children that are amenable and support any future trials that can give this feeling to all parents. This drug is vital for giving Charlie and so many others a chance at life."

Claire Liggett, whose son, Charlie (pictured), has Duchenne muscular dystrophy

Improving specialist healthcare in England

Accessing expert healthcare and support is vital for living independently and managing muscle-wasting conditions.

"Being able to access specialist healthcare and support varies significantly depending on which part of the country you live in. Having a rare condition like my sons do, we need different types of support, including access to dedicated care advice, emotional and psychological support, cardiology support, regular and ongoing physiotherapy and access to respiratory equipment. The NHS must focus on building long-term and sustainable services for people with muscle-wasting conditions which can both improve quality of life and also prevent costly hospital admissions."

Lindsay Davidson, whose two sons both have Duchenne muscular dystrophy

Supporting independent living in England

Trailblazers is our national network of young disabled people who campaign on issues important to them, and fight the social injustices they experience.

"Campaigning with the Trailblazers network is an opportunity to remove barriers to living independently. Working together we challenge the Government and organisations to make the necessary changes, such as improving disabled access to transport, leisure facilities and the high street."

Vicki Dennis, who has congenital muscular dystrophy