



Seven steps to fight muscle-wasting conditions in Northern Ireland

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 Northern Ireland

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.

“Having access to Exondys 51 is quite simply a game-changer. It has the potential to change this horrible overwhelming disorder into a more manageable condition and thus transform the life of our little boy and our family. If Joshua could get access to this drug it would mean that he could continue to do the things he loves for longer. Physical things like riding his go-kart or bike, playing football, running and playing in the park. Everyday activities that other boys can take for granted. The longer he stays on his feet the better.”

Stephen and Emma Boyd, whose son, Joshua (pictured), has Duchenne muscular dystrophy



Improving specialist healthcare in Northern Ireland

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 across the country. Having a rare condition like my son does, we need different types of support, including access to dedicated care advice, emotional and psychological support, regular and ongoing physiotherapy and to respiratory equipment. The understanding and education of teachers through the network of advisors is also important. Health and Social Care in Northern Ireland must focus on building long-term and sustainable services for people with muscle-wasting conditions to improve quality of life and also prevent costly hospital admissions.”

Graham Cloke, whose son Kenny (pictured) has Duchenne muscular dystrophy



Supporting independent living in Northern Ireland

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.”

Suzanne Glover, who has SMA