

Manifesto for Muscles 2019



Every day counts when you're living with a progressive and potentially life-threatening muscle-wasting condition. We are asking prospective parliamentary candidates to sign up to these four pledges:



1. To maintain the UK's position as a world leading centre for research excellence.

The UK has a highly valued reputation for research to develop life-changing and life-extending therapies and treatments. It is vital that the UK retains this status by attracting and nurturing the best research talent by boosting clinical trial capacity and by ensuring that researchers in UK muscle centres have the time and resources they need to conduct clinical trials.



2. To overhaul the drug approval system for new treatments for rare conditions to ensure equal access to treatments across the UK which are safe and effective.

The appraisal processes for new treatments need to reflect that rare conditions should be treated on their own merit and not be assessed in the same way as more common conditions. Excessive delays in people being able to access treatments for life-limiting conditions have occurred too often, so shorter timeframes for future appraisals are essential.



3. To strengthen and improve access to specialist NHS support which meets the needs of people living with muscle-wasting conditions.

People living with muscle-wasting conditions have a wide range of health needs. They therefore require multi-disciplinary care which brings together the expertise of professionals from a broad range of disciplines in one location to provide coordinated, patient-centred care regardless of where they live in the UK. Specialist care and support has improved over the last 10 years, but there are still significant service gaps in many parts of the UK.



4. To ensure people with muscle-wasting conditions can live independently by accessing support, facilities and amenities which they are entitled to.

People with muscle-wasting conditions need to be able to access the appropriate level of benefits for their needs through a proper and adequate assessment process. Accessible environments are also essential to ensuring that people with muscle-wasting conditions can live independently and further improvements are required to ensure that public spaces and public buildings are as accessible as possible.

Prospective parliamentary candidates can show their support by emailing
campaigns@muscular dystrophyuk.org
