

Letter to local representative template

How you can use this letter

With approximately 2,500 people in the UK living with Duchenne muscular dystrophy (DMD), your local representative (MP, MSP for Scotland, MS for Wales, and MLA for Northern Ireland) is likely to have constituents who have DMD.

Or if you or your family member has DMD, you should let them know that.

It is important that they are made aware of the challenges facing people with DMD in the UK, and what needs to improve. It is also crucial that they know how they can help remedy them.

As their constituent and potential voter, you are in an important position to inform them of these issues, and to ask for their help.

Here is a template letter that you can use to do just that.

How to contact them

You can find out who your MP, MSP, MS or MLA is, and all their contact details, below:

- For MPs: findyourmp.parliament.uk
- For MSPs (Scotland): parliament.scot/msps.aspx
- For MSs (Wales): assembly.wales/en/memhome/Pages/memhome.aspx
- For MLAs (Northern Ireland): niassembly.gov.uk/your-mlas/locate-your-mla2/

If you do write, thank you. We'd like to know if they respond as we may be able to follow up with them. You can email us at communications@duchenneuk.org or post a copy to us at Duchenne UK, Unit G24, Shepherd's Building, Charecroft Way, Hammersmith, W14 0EE.

Template letter

[Your full address]

[Date]

Dear [local representative name],

I live in [constituency name] and I am writing to you because I wanted to make you aware of the problems facing people with the muscle wasting disease Duchenne muscular dystrophy (DMD) across the UK and to ask for you to support better treatment, care, and support for them.

[If you are happy to, add details of your experience of DMD including how it impacts your life and any issues with treatment, care and support that you have experienced]

There are approximately 2,500 people in the UK living with DMD. It is a genetic life-limiting disease that causes muscle weakness and wasting, and is typically diagnosed in early childhood.

Unfortunately, people in the UK with DMD are being failed by a health system and society that neither recognises nor meets their needs.

The new report by the charity Duchenne UK, [Transforming our rare reality](#), sets out what a small community of families in the UK has had to do for themselves to get better care for their children after being diagnosed with DMD.

Postcode lottery for good DMD Care

- A key issue is that many parents of children with DMD have to project manage their own care, and that there is very much a postcode lottery across the UK as to which DMD patients receive the best standards of care, and which don't.
- As well as a perceived lack of awareness and understanding of DMD Standards of Care among individuals, it is almost always absent from NHS policies, guidance and plans.

Inadequate health technology assessments

- Although there is no cure for the disease, new medicines that have proved to slow down its progression have been developed. Duchenne UK is concerned that the current health technology appraisal system is not able to assess them quickly enough, particularly as time is of the essence when it comes to a progressive condition such as DMD.

Lack of adequate assistive technology

- As well as treatments for DMD, assistive technology is an important way to help people with DMD manage as their muscles waste and they lose limb function. Duchenne UK says that there is a serious lack of innovation in the assistive technology sector. The report highlights how, although upper arm

assistive devices have the potential to improve quality of life for people with DMD by enabling them to continue performing daily activities, most have been designed for rehabilitation to regain strength and motor control and not to assist people with DMD during activities of daily living.

Lack of awareness of DMD

- Compounding these challenges is a lack of awareness or understanding of the disease which further adds stress and anxiety to families. They are constantly having to explain to others what DMD actually is. This takes a huge toll on people with DMD and their families as it is not only frustrating to have to keep explaining something very painful, but this is usually within the context of having to fight for help and support to which they are entitled but which hasn't been forthcoming.

What needs to change

Duchenne UK is calling for help for its community and sets out a range of recommendations in the report that will improve the treatment and support for people with DMD. They include:

- For National Institute for Health and Care Excellence (NICE) to include the DMD Care UK clinical guidelines as part of its treatment guidelines for DMD.
- The UK Government should look at how trial capacity can be increased at existing Centres of Excellence. It should work with NICE and the Medicines and Healthcare products Regulatory Agency (MHRA) to produce best practice in clinical trials to ensure the information regulators need to make assessments is collected from the start, and that DMD treatments should be appraised via the HST route.
- The Minister of State for Social Security and Disability should invite a coalition of disabled people and patient advocacy groups to create a quality standard for equipment provision, in the same way that NHS England has commissioned the National Wheelchair Alliance to devise a quality standard for wheelchair services in England.
- The governments in each of the four nations should fund awareness campaigns to improve understanding of the range of neuromuscular conditions. This should be led by input from the neuromuscular community, with the relevant government department and public health body in each nation, in close collaboration with local health systems, clinicians, and other relevant specialists.

How you can help

I support Duchenne UK's campaign, and ask that you do too. Not just for your constituents who have DMD, but everyone in the UK that is living with this devastating condition.

I would be grateful if you could consider showing your support for people who live with DMD by:

- Supporting Duchenne UK's campaign on social media;

- Writing to the Minister of State for Social Security and Disability to ask them to invite a coalition of disabled people and patient advocacy groups to create a quality standard for equipment provision, in the same way that NHS England has commissioned the National Wheelchair Alliance to devise a quality standard for wheelchair services in England.
- Contacting our local NHS leadership to find out what they are doing to review and plan care for people with DMD.

Thank you for your time. I look forward to hearing from you.

Yours sincerely,

[Your name]

[Your address]