Insert MP / MSP / MLA name and address. You can find out who represents you by visiting www.theyworkforyou.com

Dear xxxx

Families affected by Duchenne muscular dystrophy during the COVID-19 pandemic

I am writing to you as one of your constituents about the lack of clear advice for families living with Duchenne muscular dystrophy (DMD). My own child/grandchild has DMD / I myself am living with DMD. *(Delete as appropriate)* Currently we are/they are/I am shielding, in accordance with government advice, but with no clarity around how and when it may be safe to resume our normal lives.

DMD is a rare progressive neuromuscular condition that affects every muscle in the body. There is no cure, and no treatment that is suitable for all those living with the condition. It mainly affects boys. Life expectancy is typically 25 – 30 years. Every year, however, our community loses children still in their teens, sometimes even younger. It is a devastating condition that affects the whole family.

*You could include additional information here about your own personal connection to DMD and the importance of access to COVID-19 advice.*

The government’s public announcements and guidance have largely ignored the needs of those living with complex conditions, instead simply advising shielding with no clear exit plan. For families like my own, this is causing considerable stress and upset.

Although we keep being told that governments will ‘follow the science’ it must be recognised that for many serious underlying health conditions, especially in children, there is little, if any, knowledge about the effects of COVID-19, and the risks it poses. I believe that a ‘one size fits all’ approach to everybody who is shielding is no longer appropriate as this crisis continues. More work is urgently needed to understand the issues facing those living with different underlying health conditions so a safe passage can be charted out of lockdown.

Across the whole UK families are in limbo, with no clear path to an exit from shielding. Lives, jobs and education are all on hold, even more so for our community. Recent announcements by the government about the UK’s path out of the current COVID-19 restrictions give little reassurance to us stating only that shielding should continue until at least the end of June, and likely longer.

You could include information here about the effect on you, your family and children.

You may want to amend the following paragraph if you are living with DMD. We want to know if we can take our children out, for example to parks, so long as social distance is observed, or even for a short drive in order to help their mental well-being. We want to know when the medical appointments our children need on a regular basis will happen - the vast majority are now either cancelled or carried out remotely with no physical checks. We want to know about the education of our children, many of whom will have Education, Health and Care Plans (amend if you live in Scotland or Northern Ireland) and/or have secondary school transition or important exams next year. *(Amend as appropriate)*

I am therefore writing to ask if you will contact the Prime Minister / First Minister (amend as appropriate – if you are writing to your MP then it will be Prime Minister, if you are writing to your MSP/MLA then it will be First Minister) to highlight how the current guidance requires urgent development and to urge the Prime Minister / First Minister (amend as appropriate) and their individual ministers to work with charities like Action Duchenne to continue to develop COVID-19 guidance to reflect the needs of those living with rare conditions like DMD.

Thank you for taking the time to consider the questions posed in this letter. I look forward to hearing from you shortly.

Yours sincerely,

YOUR NAME