**TEMPLATE LETTER TO YOUR MP**

On the next page, please find a template letter to send to your MP which you can personalise and tweak.

Make sure to include your name and postcode in your message – MP’s offices usually check this information to make sure you’re a constituent.

You can find who is your local MP, and all their contact details, through this link: <https://members.parliament.uk/members/Commons>

If you do message your MP, please let our Senior Policy Manager Will Pender ([will@duchenneuk.org](mailto:will@duchenneuk.org)) know, so we can keep track of who has been messaged, and what their response is.

If you have any questions, or need any help with this, message Will.

YOUR DETAILS INCLUDING NAME AND POSTCODE HERE

DATE

YOUR MP’S DETAILS HERE

Dear MP NAME,

I am writing to you as one of your constituents, with a son called NAME who suffers from a rare and cruel muscle wasting disease called Duchenne muscular dystrophy (DMD). There is a medicine available right now, which can slow the progression of my son’s disease. The FDA in the USA has already approved it, the MHRA and NICE are assessing it, and it’s available for free to the NHS through an Early Access Programme (EAP). But my son can’t access it yet - not because doctors don’t think it works, or because it’s expensive, but because clinics don’t have the admin capacity to process the paperwork.

Please could you write to the Department of Health and Social Care on our behalf, and ask them to give Trusts the resources they need to take part in the givinostat EAP? We are talking about a few extra blood tests, and some paperwork – a tiny cost compared to the benefit boys with DMD like my son could receive.

Our priority is getting effective medicines to our son as quickly as possible. Givinostat isn’t a cure, but the evidence suggests it’ll keep the muscles in his arms, legs, heart, and lung healthier for longer.

Time is muscle, muscle our son won’t get back. We can’t afford to wait. And right now there is a medicine available for free to the NHS, which we may not get access to at all.

If you want to know more about givinostat, or have other questions about Duchenne muscular dystrophy, you can contact a charity called Duchenne UK. This is the email address of their Senior Policy Manager Will Pender ([will@duchenneuk.org](mailto:will@duchenneuk.org)).

Yours sincerely,

YOUR NAME