**Template letter on Early Access Program**

Please find on the next page a template letter you can personalise and use to send to the CEO of your local NHS Trust if they have chosen to not take part in the Early Access Program (EAP) for givinostat.

Find the details of the relevant NHS Trust here: <https://www.stepintothenhs.nhs.uk/work-experience/smart-guide/how-to-find-and-contact-your-local-trusts>

If you cannot find an address or email for the CEO, send this letter to whatever details they provide, and ask for it to be forwarded to the CEO.

We would recommend talking to your clinician before writing to the CEO of the NHS Trust, and letting them know you intend to do so.

If you have any questions, please contact will@duchenneuk.org.

YOUR NAME

YOUR ADDRESS AND CONTACT DETAILS

DATE

CEO NAME
NHS TRUST NAME

NHS TRUST ADDRESS

Dear [CEO NAME],

I am a [parent/carer] of a person with a rare muscle wasting disease called Duchenne muscular dystrophy (DMD), and I am writing to you to urge you in the strongest possible terms to give [DOCTOR’S NAME HERE] and their team the resources they need to take part in a compassionate use scheme for a medicine which could vastly improve the life of my child/the child I care for.

DMD, the most common form and severe form of muscular dystrophy, is a horribly cruel and devastating disease. You can find more on DMD at the website of Duchenne UK (https://www.duchenneuk.org/about-duchenne-muscular-dystrophy). There is no cure, but there is a promising treatment which is approved in the US, will likely be approved in the UK in 2025, and is currently available free to the NHS.

It is called givinostat, and the company which makes it, ITF Pharma UK, are making givinostat available for free to the NHS through an Early Access Program (EAP). But having talked to [DOCTOR’S NAME HERE] I have learned that we cannot access givinostat through your NHS Trust because of [REASON].

This is completely unacceptable. Patients across Europe are already benefiting from the EAP. I am sure you can see the injustice in patients in other countries being able to access this medicine, while it is denied to us.

Please can you rectify this situation and, if not, please can you explain why you will be denying a free medicine to patients who need it.

Yours sincerely,

[YOUR NAME HERE]