

Date 16/04/2025  
Your Ref  
Our Ref 9889

Enquiries to Richard Mutch  
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Dear

## FREEDOM OF INFORMATION – THE EARLY ACCESS PROGRAM FOR GIVINOSTAT

I write in response to your request for information in relation to the Early Access Program for Givinostat.

Question:

- I would like to request an update on the Early Access Program EAP for Givinostat. ~~~~~ has Duchenne Muscular Dystrophy and qualifies for EAP for Givinostat.

We have recently been aired on STV news to share our story and frustrations. The NHS Lothian response if I am honest was a lie. "We review eligibility for EAP on a case by case basis and cannot discuss specific patient cases". You are not reviewing this on a case by case basis because not 1 child in Scotland has been referred for the EAP to date.

I would like to know for ~~~~~, what is the current status of the EAP for Givinostat (Duvyzat) treatment for DMD?

Answer:

As the request is in relation to the treatment of an individual we have passed your correspondence onto our Patient Experience Team to take forward - [loth.feedback@nhs.scot](mailto:loth.feedback@nhs.scot).

The information you have requested is specific to the care of an individual and to answer it would require access to the personal information. I must advise you that the information you have requested comes under Section 38 of the Freedom of Information Act (Scotland) 2002 – Personal Information. The Act says:

- Where the person making the request has asked for information about themselves – or someone they are the legal guardian/Power of Attorney for (Section 38(1)(a)). There is an absolute exemption where the information constitutes personal data of which the person is subject. This is known as a subject access request and falls under the remit of the Data Protection Act (2018). The rules under the DPA will determine whether the person has a right to the information. The application cannot be considered under the FOI(S)A 2002.

Headquarters  
Mainpoint  
102 West Port  
Edinburgh EH3 9DN

Chair Professor John Connaghan CBE  
Chief Executive Professor Caroline Hiscox  
*Lothian NHS Board is the common name of Lothian Health Board*



The effect of the exemption is not to deny individuals a right to access information about themselves but to ensure the right is exercised under the DPA.

I am sorry I cannot help with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at [www.itspublicknowledge.info/Appeal](http://www.itspublicknowledge.info/Appeal). If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhslothian.scot/FOI/Pages/default.aspx>

Yours sincerely

**ALISON MACDONALD**  
**Executive Director, Nursing**  
Cc: Chief Executive