

Date: 07 April 2025  
Our ref: K: FOI/Ref: 2025-000095  
Email: [NSS.DevServicesFOI@nhs.scot](mailto:NSS.DevServicesFOI@nhs.scot)

**Freedom of Information Reference: FOI-2025-000095 – Givinostat Early Access Program.**

I refer to your freedom of information request that we received on 19 March 2025 requesting the following information.

**I am writing from a patient-led medical research charity focused on a disease called Duchenne muscular dystrophy (DMD). There is currently a compassionate use/free of charge scheme available to the NHS called the Early Access Programme (EAP) which makes a medicine called givinostat available to specialist neuromuscular clinics for free.**

**Has the PASAG assessed the givinostat EAP, and if so, what was its guidance to health boards?**

**In addition, does the PASAG play a role in assessing or providing resources to health boards for schemes such as these?**

We have now completed the search of our records and can provide you with the following information:

**Has the PASAG assessed the givinostat EAP, and if so, what was its guidance to health boards?**

**In addition, does the PASAG play a role in assessing or providing resources to health boards for schemes such as these?**

The Patient Access Scheme Assessment Group (PASAG) Secretariat within the National Procurement (NP) Directorate of NHS National Services Scotland (NSS) which coordinates and reviews the Pre-Health Technology Assessment Free of Charge (pre-HTA FOC) schemes proposed by pharmaceutical companies. NSS after consultation and agreement with Health Boards' (HBs) Area Drugs & Therapeutics Committees in Scotland have issued guidance on Pre-HTA FOC medicine pricing schemes, which can be viewed in the Healthcare Improvement Scotland website: [Pre-HTA FOC Scheme Guidance](#)

Under Section 33(1)(b) of FOISA "Substantial Prejudice to Commercial Interests" NSS cannot disclose this information as it is considered commercially sensitive.

NSS has concluded that disclosing this information could harm the commercial interests of both NSS and our suppliers. Given the market for Free of Charge (FOC) and Compassionate Use Schemes in the UK is limited, releasing such details could provide competitors with insights into our supplier's commercial offerings, affecting future market competitiveness. Additionally, sharing this information could negatively impact NSS's ability to procure goods and services at the most advantageous prices in future.



Chair Keith Redpath  
Chief Executive Mary Morgan

*NHS National Services Scotland is the common name of the Common Services Agency for the Scottish Health Service*

As the Section 33(1)(b) exemption is a “qualified” exemption, a “Public Interest Test” must be carried out in order to determine if the exemption can be applied.

FOISA does not define the public interest. It has been described elsewhere as “something which is of serious concern and benefit to the public”, not merely something of individual interest. It has also been described as “something that is “in the interest of the public”, not merely “of interest to the public.” In other words, it serves the interests of the public.

NSS has recognised that there is always a strong public interest in Scottish public authorities acting in an open and transparent manner, however in this case NSS has determined that there is an even stronger public interest in NSS being able to procure goods and services at the best possible value to the public purse. Therefore, on this occasion NSS has decided that the public interest lies in the withholding of this information resulting in the application of the exemption.

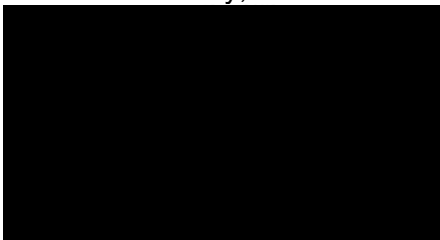
I trust you will find the information of assistance and if you require any further information, please do not hesitate to contact me.

If you are unhappy with any aspect of how we have dealt with your request, you can make representations to us asking us to review the handling of your request. Please write to the Associate Director Governance and Board Services (Board Secretary) at the email address [nss.foi@nhs.scot](mailto:nss.foi@nhs.scot) within 40 working days of the date of this correspondence.

If after a review you are still unhappy, you also have the right to apply to the Scottish Information Commissioner, who can be contacted at Kinburn Castle, St Andrews, Fife, KY16 9DS, or via their [online application form](#).

If you have any queries about this letter, please contact me at the above address.

Yours sincerely,



Chair Keith Redpath  
Chief Executive Mary Morgan

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