

Dear

FREEDOM OF INFORMATION – DMD

I write in response to your request for information in relation to Duchenne muscular dystrophy (DMD) within NHS Lothian.

Question:

- I would like to request the following information in regard to the treatment of Duchenne muscular dystrophy (DMD) by your organisation:
 - Does your organisation commission any services for people with DMD?
 - If no, does your organisation expect to commission services for DMD in the future?
 - If yes, what services for people with DMD does your organisation commission?
 - How many people with DMD does your organisation serve?
 - Does your organisation have any DMD-specific (or muscle-wasting disease-specific) policies or guidance?
 - Do any of your organisation's strategies, objectives, plans, performance indicators, audits, inspections, or similar, cite DMD (or any muscle-wasting disease) or use either as a metric?
 - Is your organisation aware of the work of DMD Care UK (<https://dmdcareuk.org/>)?

Answer:

1.	No, not within the NHS in Scotland.
2.	Paediatric patients - approximately 22.
3.	We use guidance from Scottish Muscle Network and CAREDMD UK.
4.	No.
5.	Yes.

I hope the information provided helps 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. 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, Midwifery and AHPs
Cc: Chief Executive