

Date: 22/03/2024  
Your Ref:  
Our Ref: 8452

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Dear

## FREEDOM OF INFORMATION – HAEMOPHILIA

I write in response to your request for information in relation to Haemophilia.

### Question:

- Professor Ludlum Haemophiliac data on patients with year of birth 1970/71 that had been either under care at Edinburgh Royal Infirmary or Raigmore Hospital as a consultant from 1980 - 83. Also any pseudonyms these patients may have been given.

### Answer:

I am advised that we do not hold this information in an extractable format. We would suggest either a subject access request (if the data requested is in relation to yourself), or we can deal with requests for access to patient identifiable information on deceased third parties through the Caldicott Guardian process.

I would advise that you contact the NHS Lothian SAR Team - [loth.sarteam@nhs.scot](mailto:loth.sarteam@nhs.scot) and they can process this appropriately.

### Question:

- What clinical trials had Professor Ludlum carried out on Mild Haemophiliac A patients 1980 - 83?

### Answer:

We do not hold any information on clinical trials carried out by Professor Ludlam in the period 1980 – 83. As per Section 17 of the Freedom of Information (Scotland) Act 2002 formally I must advise you that we do not hold this information.

### Question:

- What clinical trials / studies had Professor Ludlum carried out on Mild Haemophilia A siblings?

### Answer:

No time period was detailed so we looked across documents we had around Prof Ludlam's clinical trials regardless of period. We only have research protocols and ethics applications.

The data on these for the patients to be recruited are all around clinical characteristics, and do not specify any need for family relationships.

Question:

- Also had there been any of Professor Ludlum mild haemophiliacs who had received concentrates/cryoprecipitate from 1980-83 on any viral inactivated or placebo clinical trials?

Answer:

See above: We do not hold any information on clinical trials carried out by Professor Ludlam in the period 1980 – 83. As per Section 17 of the Freedom of Information (Scotland) Act 2002 formally I must advise you that we do not hold this information.

I am sorry I cannot help further 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.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

**ALISON MACDONALD**  
**Executive Director, Nursing, Midwifery and AHPs**  
Cc: Chief Executive