

Date 11/06/2025
Your Ref
Our Ref 10109

Enquiries to Richard Mutch
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Dear

FREEDOM OF INFORMATION - RARE LIVER CONDITIONS

I write in response to your request for information in relation to rare liver conditions.

Question:

- Where in your board area is there a service for people with rare liver conditions, such as PBC?

Answer:

We have consultant hepatologists (RIE) and gastroenterologists (St John's) who look after rare liver conditions including PBC.

Question:

- What provision is there for clinicians in your NHS board area to access clinical expert groups / clinical networks to discuss the management of people with rare liver conditions, such as PBC?

Answer:

Gastroenterologists at St John's will refer difficult or high risk patients to hepatology at RIE.

Hepatologists within RIE have regular MDTs where complex patients can be discussed with colleagues.

One of the hepatologists at RIE also contributes to a Scottish Autoimmune Liver Disease/PBC Group which meets virtually every 2 months to discuss cases from around Scotland.

Question:

- Do clinicians working in your board area have access to the iLFT?

Answer:

No

Question:

- If no, is there plans to do so?

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

Answer:

Not currently, although our laboratory staff are still considering this.

Question:

- What are the current challenges to delivering iLFT in your board area?

Answer:

The current iLFT platform does not interact with the RIE laboratory machines so introduction of this would require a number of hardware changes.

Question:

- What is the process currently for GPs diagnosing, treating and supporting patients with suspected PBC?

Answer:

We have a pathway for GPs for investigating abnormal liver enzymes (similar to that used by iLFTs) which includes routine testing for PBC and referral to secondary care if this is detected.

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.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive