

Date: 09/04/2024
Your Ref:
Our Ref: 8521

Enquiries to : Richard Mutch
Extension: 35687
Direct Line: 0131 465 5687
loth.freedomofinformation@nhs.scot
richard.mutch@nhs.scot

Dear

FREEDOM OF INFORMATION – GLYCOGEN STORAGE DISEASE

I write in response to your request for information in relation to glycogen storage disease.

Question:

Specific to the time period between April 2018 until March 2024. Please break the information down to year-on-year i.e 2018/19, 2019/20, 2020/21 etc.

- How many people have been diagnosed with glycogen storage disease in Scotland since records began?
- How many people have been diagnosed with each type of Glycogen storage disease (1,2,3,4, 5,6,7,8,9,10,11,12,13,14,15,16,) (**excluding** the sub-types a, b, c or d for now)?
- How many metabolic centres are there in Scotland?

Answer:

I cannot answer questions for the whole of Scotland as we only cover the NHS Lothian area.

All people with glycogen storage disease who are resident in NHS Lothian are looked after by the Scottish IMD Service, which is nationally commissioned and managed from NHS Greater Glasgow and Clyde.

The numbers of patients for each form of GSD are all less than 5. Due to the small numbers involved it is not possible to give further detail. This information is considered exempt under Section 38(1b) of the Freedom of Information (Scotland) Act 2002 – personal information.

Question:

- How much Scot Gov funding has been received to the metabolic service at NHS Lothian
- Who oversees the Inherited Metabolic service in Scotland?

Answer:

As detailed above this is a nationally commissioned and managed provided by NHS Greater Glasgow and Clyde.

Question:

- Who is the current lead clinician at Lothian?

Answer:

The lead clinician is Dr Alison Cozens, Consultant in Paediatric Inherited Metabolic Medicine

The Medical Director for NHS Lothian is Miss Tracey Gillies.

Question:

- Who was the lead dietetic specialist between April 2018 and March 2024 at Lothian?
- Who was the lead nurse specialist at Lothian between April 2018 and March 2024?
- Who is responsible for overseeing **each** of those professionals?

Answer:

There are no clinical, dietetic or nursing leads specifically for NHS Lothian.

The Nurse Director for NHS Lothian is Ms Alison McDonald.

Question:

- How much funding via donations have the Metabolic service received between 2018 and 2024?
- How are government funds distributed across IMD Lothian?
 - Please itemise year-in-year where possible.
- Does the sum from Scot Gov cover salaries?
- If the funds are separate, what is the salary of the
 - Lead clinician?
 - Lead dietetic specialist?
 - Lead nurse specialist?

Answer:

There is no metabolic fund in Lothian receiving donations of any kind.

Funding for the service is provided by National Services Scotland, not directly by NHS Lothian.

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, Midwifery and AHPs
Cc: Chief Executive