

Freedom of Information request 312-20

Request

We have a freedom of information request related to the incidence and treatment of some inherited metabolic disorders. Could you please provide answers to the following four questions?

Q1. Within your trust, how many patients currently have a diagnosis for:

Fabry Disease
Gaucher Disease
MPS II (Hunter Syndrome)

Q2. Of the patients above, how many have been newly diagnosed within the past 3 months for:

Fabry Disease
Gaucher Disease
MPS II (Hunter Syndrome)

Q3. How many patients (including any patients whose treatment is on hold due to Covid-shielding) are being treated at this point in time with:

Replagal (agalsidase alpha)
Fabrazyme (agalsidase beta)
Galafold (migalastat)
VPRIV (velaglucerase alfa)
Cerezyme (imiglucerase)
Cerdelga (eliglustat)
Zavesca (miglustat)
Any other treatment for Fabry disease [please state which treatments]
Any other treatment for Gaucher disease [please state which treatments]

Q4. Of the patients being treated for Fabry disease can you please provide the numbers of patients being treated through homecare?

Response

1. NHS Borders do not treat patients with any of the conditions listed, these patients would be treated within NHS Lothian on our behalf, therefore under Section 25 of the FOI(S)A 2002 this data is accessible elsewhere.
2. NHS Borders do not treat patients with any of the conditions listed, these patients would be treated within NHS Lothian on our behalf, therefore under Section 25 of the FOI(S)A 2002 this data is accessible elsewhere.

3. None.

4. NHS Borders do not treat patients with Fabry disease locally, these patients would be treated within NHS Lothian on our behalf, therefore under Section 25 of the FOI(S)A 2002 this data is accessible elsewhere..

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to, Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or foi.enquiries@borders.scot.nhs.uk.

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the reference number **312-20** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.