

Date: **21 November 2019**

Our reference: **FOIRQ5239**

Dear Sir/Madam,

Thank you for your request for information processed under the Freedom of Information Act 2000. Please see our response to your request below:

Your Request

Q1. Within your trust how many patients have been treated, in the past 3 months [latest 3 months available] for Fabry Disease?

Q2. Of these patients [from question 1], how many have been treated with the following [please state the number per treatment]

Replagal (agalsidase alpha)

Fabrazyme (agalsidase beta)

Galafold (migalastat)

Other [please state which treatments]

Q3. Within your trust how many patients have been treated, in the past 3 months [latest 3 months available] for Gaucher's Disease?

Q4. Of these patients [from question 3], how many have been treated with the following [please state the number per treatment]

VPRIV (velaglucerase alfa)

Cerezyme (imiglucerase)

Cerdelga (eliglustat)

Zavesca (miglustat)

Other [please state which treatments]

If you are unable to link diagnosis and treatment, please state the number of patients on each of the following treatments;

Replagal (agalsidase alpha)

Fabrazyme (agalsidase beta)

Galafold (migalastat)

VPRIV (velaglucerase alfa)

Cerezyme (imiglucerase)

Cerdelga (eliglustat)

Zavesca (miglustat)

Our Request for Clarification

We provided you with the following advice and assistance:

- The clinical coding for both Fabry disease and Gaucher's disease is identical and there is no way to differentiate between the two conditions using the same coding. We are therefore unable to provide the information you have requested; because we cannot distinguish between the two conditions. However, we did advise you that the number of patients that were diagnosed with either Fabry Disease or Gaucher's Disease could be provided for the time period you requested. We asked you confirm whether you would you like us to provide a response on this basis?

Your Response to Our Request for Clarification

Thank you for your response. Please could you proceed and provide the data for both Fabry and Gauchers's combined.

Our Response

Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is a single site, specialist tertiary paediatric trust. The Trust can only provide the number of distinct patients diagnosed with either Fabry or Gaucher's disease; because both diseases are coded identically (ICD-10 Code E752), which is the same code used for other related diseases. We can neither differentiate between the two disease; nor can we match the patient and diagnosis with the treatments listed.

The following information is a combined number of distinct patients diagnosed with either Fabry or Gaucher's disease up to the date your clarification was received on 10/006/2019:

March 2019 - <5**

April 2019 – 19

May 2019 – 6

If you are unable to link diagnosis and treatment, please state the number of patients on each of the following treatments;

Please see our response to each treatment listed below:

*Replagal (agalsidase alpha) - <5***

*Fabrazyme (agalsidase beta) - <5**

*Galafold (migalastat) - <5***

*VPRIV (velaglucerase alfa) - <5***

Cerezyme (imiglucerase)

Cerdelga (eliglustat) - 7
Zavesca (miglustat) - 7

Please note: **The Trust is unable to respond to information where there have been fewer than five data subjects (<5). Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is withholding this information under Section 40 of the Freedom of Information Act (FOIA) 2000 in order to reduce the risk of identifying an individual. The Trust's view in providing this information would significantly increase the risk of individuals being identified.

The Trust believes that Sections 40(2) of the FOIA is applicable in withholding the information as disclosure could lead to individuals being identified; which is considered to be a breach of their rights under the Data Protection Act (DPA) 2018. The grounds for applying this exemption are as follows:

- In the context of your request, this data is third party information. The Trust categorises the information about our patients' health as information falling within paragraph (e) of the definition of "sensitive personal data" in s.2 of the DPA 2018. As such, Section 40(2) of the FOIA applies to this information, as does the Trust's duty of confidentiality. Therefore under s.2(3)(f)(ii) of the FOIA, there is an absolute exemption from disclosure on the grounds that it would contravene the First Data Protection Principle.
- The Trust has a duty under the DPA 2018 and the First Data Protection Principle to process personal data regarding the Trust's patients fairly and lawfully and, in particular, not process data unless at least one of the conditions in Schedule 2 DPA is met, and in the case of sensitive personal data, at least one of the conditions in Schedule 3 DPA is also met.
- The Act has defined "sensitive personal data" to include data on the "physical or mental health or condition" of a person (s.2(e) DPA). Any medical information about specific individual falls within this category and disclosure of this data to a FOI applicant would be processing sensitive personal data of those patients.

In line with the guidance from the Information Commissioner's Office based upon the requirements of the Data Protection Act the Trust has considered first whether it would be "fair" to process and disclose the requested information, and whether it would be lawful to disclose the requested information before considering whether any Schedule 2 and Schedule 3 conditions have been met. Disclosing medical information to the public regarding the Trust's patients is likely to lead to emotional distress of the patients and their families. It is also the Trust's position that there is a reasonable expectation on the part of the Trust's patients and their families that their sensitive personal data would not be disclosed to FOI applicants.

A breach of this expectation would have the effect of the data being processed unfairly. The information that forms part of the medical records of an individual is therefore implicitly confidential. The courts and the Information Commissioner have long recognised the strong public interest inherent within keeping confidential medical information confidential. The Trust holds the view that Section 41 (1) of the FOIA is applicable for the reasons that: the information was obtained by the Trust; it has the necessary quality of confidence (being neither generally accessible nor trivial); and disclosure of this information to an FOI applicant would give rise to an actionable breach of confidence.

Please note:

The information we have provided under the Freedom of Information Act 2000 is the information held up to the date your request was received by the Trust.

We trust the information provided is sufficient and helpful in answering your request for information. If, however, you have any queries in relation to your request, please do not hesitate to contact the FOI Team and quote the above reference number on any related correspondence.

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Yours sincerely

Freedom of Information team

Great Ormond Street Hospital for Children NHS Foundation Trust
Email: foiteam@gosh.nhs.uk

[Enclosed – Your rights – see next page]

Your Rights

If you are dissatisfied with the response you have received to your request for information, please contact the FOI team and quote your reference number on all correspondence relating to your request.

You can also write to the Head of Quality & Safety at the following address:

Quality & Safety team
Great Ormond Street Hospital
LONDON
WC1N 3JH

If you are still not satisfied with your response, you also have the right to appeal to the Information Commissioner.

You can contact the Information Commissioner's Office at the following address:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF