

FOI 3249

20<sup>th</sup> August 2025

## **FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST**

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### **HAE:**

**Question 1: In the past 3 months [latest 3 months available] how many patients have received the following treatments [for any disease]:**

**Berinert (Human C1-esterase inhibitor)**

**Cinryze (Human C1-esterase inhibitor)**

**Orladeyo (Berotralstat)**

**Takhzyro (Lanadelumab)**

**Ruconest (Recombinant human C1-esterase inhibitor)**

**Firazyr (Icatibant injection)**

**Icatibant - any brand except Firazyr**

### **Response:**

**Berinert (Human C1-esterase inhibitor) - <5**

**Cinryze (Human C1-esterase inhibitor) - <5**

**Orladeyo (Berotralstat) - <5**

**Takhzyro (Lanadelumab) - <5**

**Ruconest (Recombinant human C1-esterase inhibitor) - <5**

**Firazyr (Icatibant injection) – <5**

**Icatibant - any brand except Firazyr – <5**

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the information requested. In addition the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

S 40 (2) (third party information) of the Freedom of Information Act 2000 has been applied to exempt the redacted information from disclosure. The Trust does not consider the disclosure of the redacted information to be fair to the individuals concerned as there is the potential risk of identification of an individual(s) which they would not expect, and which would therefore breach the fairness element of the first principle of the Data Protection Act 2018.

**IG:**

**Question 2: In the past 3 months how many patients have received the following treatment for any disease?**

**Octagam  
Gamunex  
Intratect  
Kiovig  
Gamten  
Panzyga  
Xembify  
Cuvitru  
Cutaquig  
Hyqvia**

**Response:**

**Octagam - <5  
Gamunex - 30  
Intratect - 6  
Kiovig - <5  
Gamten - <5  
Panzyga - 11  
Xembify - <5  
Cuvitru – <5  
Cutaquig - <5  
Hyqvia – <5**

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**Question 3: In the past 3 months, how many patients have received any immunoglobulin treatment for the following diseases:**

**Primary immunodeficiency (PID)  
Secondary immunodeficiency (SID)  
Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)**

**Response:**

This information is not recorded centrally. Data currently held cannot be linked to a single diagnosis and therefore retrieving it would involve a manual search of individual

patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

Under section 12 of the Freedom of Information Act 2000, Public Authorities are not obliged to comply with an information request where to do so would exceed the cost limit.

In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

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