

Date: **13 August 2020**

Our reference: **FOIRQ5897**

Dear Sir/Madam,

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

**Your Request and Our Response (in Bold)**

Q1. How many adult and paediatric patients registered with your Haemophilia Centre suffer from the following conditions:

- Haemophilia A **180**
- Haemophilia B **48**
- Von Willebrand Disease **193**

Q2. In the last three months, how many patients have been treated with the following:

- Advate
- Adynovi
- Elocta
- Esperoct
- Factor Eight Inhibitor Bypass Activity (FEIBA)
- Hemlibra
- Jivi
- NovoEight
- NovoSeven RT
- Obizur
- Refacto AF
- Alprolix
- BeneFIX
- Idelvion
- Refixia
- Rixubis
- Gene therapy (for Haemophilia B)
- DDAVP (desmopressin)
- Tranexamic acid
- Veyvondi
- Voncento
- Wilate

The Trust is withholding this information under Section 40 of the Freedom of Information Act (FOIA) 2000.

The Trust is unable to respond to your request for a breakdown of information where a low number of patients of 5 or less (<5) are linked to specific treatments. We are withholding this information in order to reduce the risk of identifying an individual as disclosure would significantly increase the risk of individuals being identified and could potentially be a breach of their rights under the Data Protection Act (DPA) 2018.

The Trust categorises the information about our patients' health as information falling under "sensitive personal data" where disclosing medical information to the public relating to our 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.

The Trust has a duty of confidentiality and a breach of this expectation would have the effect of the data being processed unfairly, which is information that forms part of the medical records of an individual that is 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 also 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 a FOI applicant would give rise to an actionable breach of confidence. Your request is therefore exempt under Section 40(2) and Section 41(1) of the FOIA.

**Please note:**

The United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) manages the National Haemophilia Database as they work with Haemophilia Centres in England, Scotland, Northern Ireland and Wales.

The UKHCDO is where information relating to blood disorders is centrally reported on the number of patients and treatments: including statistical data relating to Von Willebrand Disease, Haemophilia A and Haemophilia B. The latest annual report for 2018/2019 is available on the UKHCDO website link below:

<http://www.ukhcdo.org/wp-content/uploads/2019/11/UKHCDO-Annual-Report-2019.pdf>

Q3. Of the Haemophilia A patients treated in the last three months, could you please tell us the number of mild, moderate and severe patients. **Mild 7, Moderate 12, Severe 89**

Q4. Of the Haemophilia A patients treated in the last three months, could you please tell us the number of patients with and without Factor VIII Inhibitors. **19**

Q5. Of the Haemophilia B patients treated in the last three months, could you please tell us the number of mild, moderate and severe patients. **Mild \* <5, Moderate\* <5, 2 Severe 21**

**The Trust is withholding this information under Section 40 of the Freedom of Information Act (FOIA) 2000.**

**The Trust is unable to respond to your request for a breakdown of information where a low number of patients of 5 or less (<5) are linked to specific treatments. We are withholding this information in order to reduce the risk of identifying an individual as disclosure would significantly increase the risk of individuals being identified and could potentially be a breach of their rights under the Data Protection Act DPA) 2018.**

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**Please note**

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

We hope the information provided is sufficient and helpful in answering your questions, issues or concerns. Should you have any further queries in relation to this request, please do not hesitate to contact the FOI Team and quote the above reference number on any related correspondence.

**Re-use of information**

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Yours sincerely

**Freedom of Information team**

Great Ormond Street Hospital for Children NHS Foundation Trust

Email: [foiteam@gosh.nhs.uk](mailto:foiteam@gosh.nhs.uk)

**[Enclosed – Your rights – see next page]**

### **Your Rights**

Should you have any questions relating to the response you have received to your request for information, please do not hesitate to contact the FOI Team. Alternatively, you are entitled to make a request for an internal review within two months from the date of receiving our final response to your original 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, however, you remain dissatisfied with the outcome of the internal review then you have the right to appeal to the Information Commissioner as the final stage of the FOI process. You can contact the Information Commissioner's Office at the following address:

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

Telephone: 0303 123 1113  
Fax: 01625 524510