

Date: **3 October 2019**

Our reference: **FOIRQ5439**

Dear Sir/Madam,

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

Your Request

I am writing to request some information about the treatment of haemophilia and also von Willebrand disease.

Hopefully you can supply the information as follows:

I understand these diseases have a form of register. How many are on your registers for:

- . Haemophilia A*
- . Haemophilia B*
- Von Willebrand Disease – are you able to say how many are under 18 years old as well?*
Over the last 3 months, how many patients with Haemophilia A have been treated with:

- . Advate*
- . Afstyla*
- . Elocta*
- . Emicizumab (Hemlibra)*
- . Helixate*
- . Kogenate*
- . Novoseven RT*
- . Novoeight*
- . Nuwiq*
- . Refacto AF*
- . Factor Eight Inhibitor Bypass Activity*

If you are able to split the above by patients who have mild, moderate and severe Haemophilia, that would be useful, thanks.

Over the last year, how many patients have been treated with:

- . Alphanate*
- . DDAVP (desmopressin)*
- . Haemate P*

- *Trabexamic acid*
- *Veyvondi*
- *Voncento*
- *Willate*
- *Willfact*
- *Willfactin*
- *Alprolix*
- *BeneFIX*
- *Idelvion*
- *Refixia*
- *Rixubis*

Our Response

Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is a single site, specialist tertiary paediatric trust. The information you have requested is considered to be personally and commercially sensitive data, in which, you are requesting a specific breakdown of details pertaining to GOSH patients covering the last three months. The Trust has a duty to protect the personal data of patients and ensure that patient confidentiality is not compromised. Your request is therefore exempt under Section 40 (2) (Personal Information) of the Freedom of Information Act (FOIA) 2000. Please see note below **

Please note** The Trust is unable to respond to information where you have requested a breakdown of information due to a low number of patients of 5 or less (<5). Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is withholding this information in order to reduce the risk of identifying an individual. The Trust is of the view that in providing this information it would significantly increase the risk of individuals being identified. The Trust believes that Sections 40(2) is applicable in withholding the information that 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 Principles.
- 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 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 available on the website covers financial year 2017/2018, which you can access via the following website link:

www.ukhcdo.org/wp-content/uploads/2019/04/2018_UKHCDO_Annual_Report_2017_18_Data.pdf

Please note:

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

We trust the information provided is sufficient and helped to answer any issues, concerns or questions. 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.

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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