

Haemophilia B & Von Willebrand Treatments

Reference Number: RDF1775-23

Date of Response: 21/08/2023

Further to your Freedom of Information Act request, please find the Trust's response(s) below:

Please be aware that the Royal Devon University Healthcare NHS Foundation Trust (Royal Devon) has existed since 1st April 2022 following the integration of the Northern Devon Healthcare NHS Trust (known as Northern Services) and the Royal Devon and Exeter NHS Foundation Trust (known as Eastern Services).

Could you please provide answers to the following five questions related to the incidence and treatment of Haemophilia B and Von Willebrand Disease?

Q1. How many patients has your Trust treated (for any medical condition) in the past 3 months with the following drugs:*

	Trust total
Alphanate	0
Alprolix	* <5
BeneFIX	* <5
HaemateP	0
Idelvion	0
Refixia	0
Rixubis	0
Veyvondi	0
Voncento	* <5
Wilate	0
Willfact	0

[] Patient numbers provided by Blood Transfusion Team for period May-Jul 2023*

Q2. How many patients have been treated in the past 3 months with:

- Gene therapy for Haemophilia B ONLY* : The Trust Haematology consultant has confirmed that gene therapy treatments are not currently carried out by the Trust

	Trust totals
Desmopressin for Von Willebrand Disease ONLY*	* <5
Tranexamic Acid for Von Willebrand Disease ONLY*	7

[] We cannot say for certain these patients were treated for the specific condition listed, just that they were prescribed a drug and have an active diagnosis of Von Willebrand disease recorded on their medical record.*

Q3. *Of the patients that were treated with Veyvondi in the past 3 months, how many patients received treatment:*

- *During surgery:* N/A – no patients treated with Veyvondi in past 3 months
- *On demand to treat bleeding episodes :* N/A – no patients treated with Veyvondi in past 3 months

Q4. *Of the patients that were treated with Voncento in the past 3 months, how many patients received treatment:*

- *During surgery* 0* patients (*1 patient treated on the day of procedure)
- *On demand to treat bleeding episodes* *<5 patients.

Q5. *How many patients are registered with your trust for the following diseases:*

- *Haemophilia B* 13 patients
- *Von Willebrand Disease* 75 patients
- *Von Willebrand Disease - paediatric patients (age 17 or under)* 11 patients

***<5 - Section 40 (2) - Less than five**

In accordance with Section 40 (2) of the Freedom of Information Act 2000, we are unable to provide figures where the number of patients/staff is less than or equal to five and could risk the identification of those patients and breach Caldicott principles. In these cases ≤5 is used to indicate that a figure between 1 and 5 is being suppressed.

This follows NHS Digital (formerly HSCIC) analysis guidance (2014) which states that small numbers within local authorities, wards, postcode districts, CCG's providers and Trusts may allow identification of patients and should not be published.