Reference:	FOI.20067 & 20068.26
Subject:	Treatments
Date of Request:	31 March 2026

Requested:

FOI.20067

Hereditary Angioedema (HAE):

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

Immunoglobulin (IG)

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

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)

FOI.20068

Haemophilia A

1. In the past 12 months [latest 12 months available], how many patients have been diagnosed with the each of the following conditions in your Trust:
   - Haemophilia A
   - Acquired Haemophilia A (AHA)
   - Congenital Haemophilia A with inhibitors CHAwI)

2. In the last twelve months [latest 12 months available], how many pts with Haemophilia A, have been treated with each of the following products in your Trust:

- Factor Eight Inhibitor Bypass Activity (FEIBA)
- Hemlibra (standalone)
- Hemlibra in combination with NovoSeven RT
- Hemlibra in combination with Cevenfacta
- NovoSeven RT
- Obizur
- Cevenfacta

3. In the last twelve months [latest 12 months available], how many patients with Acquired Haemophilia A, have been treated with each of the following products in your Trust:
   - Factor Eight Inhibitor Bypass Activity (FEIBA)
   - NovoSeven RT
   - Obizur
   - Cevenfacta

4. In the last twelve months [latest 12 months available], how many pts with Congenital Haemophilia A with Inhibitors have been treated with each of the following products in your Trust?
   - Factor Eight Inhibitor Bypass Activity (FEIBA)
   - Hemlibra (standalone)
   - Hemlibra in combination with NovoSeven RT
   - Hemlibra in combination with Cevenfacta
   - Hemlibra in combination with FEIBA
   - Helimbra in combination with Factor VIII
   - NovoSeven RT
   - Obizur
   - Cevenfacta

Prothrombin Complex Concentrate (PCC)

5. What is the total Prothrombin Complex Concentrate usage in International Units (IUs) for your Trust over the last 12 months [latest 12 months available] for each of the products below in your Trust?
   - Prothromplex
   - Beriplex
   - Octaplex

6. Can you share the Prothrombin Complex Concentrate usage in International Units for your Trust in the last 12 months [latest 12 months available] within each of the following departments, and which PCC is used?
   - Prothromplex
   - Beriplex
   - Octaplex

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with all the information requested, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information Act 2000 (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or

2½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

To provide you with the information requested for question 6, the UHB would be required to undertake a manual search of blood bank records for the requested twelve (12) month period, to identify the number of international units issued to each of the listed departments, as this is not recorded centrally.

The UHB is therefore applying an exemption under Section 12 of the FoIA, which provides an exemption from a public authority's obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit.

However, under Section 16 of the FoIA, we are required as a public authority, to provide advice and assistance so far as it is reasonable to individuals who have made a request under the FoIA, which can include assisting a requestor to further refine their request.

You may further refine your request by reducing the timeframe requested e.g. a three (3) month period. However, the UHB would still be required to manually trawl Prothrombin Complex Concentrate (PCC) issue records to identify any information that may fulfil your request.

Additionally, where the figures in the tables have been replaced with an asterisk (*), the UHB is unable to provide you with the exact number of patients due to the low number of cases (less than 5), as there is a potential risk of identifying individuals if this was disclosed. The UHB is therefore withholding this detail under Section 40(2) of the FoIA. This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations (UK GDPR) as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles of the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

In reaching this decision, the DPA and UK GDPR define personal data as data that relates to a living individual who can be identified solely from that data or from that data and other information, which is in the possession of the data controller.

FOI.18942

1. The UHB provides within the table below, the number of patients that have received the listed treatments, for any disease, during the period 1 January to 31 March 2026.

Treatment	Number
Berinert (Human C1-esterase inhibitor)	0
Cinryze (Human C1-esterase inhibitor)	0
Orladeyo (Berotralstat)	0
Takhzyro (Lanadelumab)	0
Ruconest (Recombinant human C1-esterase inhibitor)	0
Firazyr (Icatibant injection)	0
Icatibant - any brand except Firazyr	*

2. The UHB provides within the table below, the number of patients that have received the listed treatments, for any disease, during the period 1 January to 31 March 2026.

Treatment	Number
Octagam	*
Gamunex	11
Intratect	0
Kiovig	0
Gamten	0
Panzyga	0
Xembify	0
Cuvitru	0
Cutaquig	0
Hyqvia	0

3. The UHB provides within the table below, the number of patients that have received the listed Immunoglobulin treatments, for the conditions listed, during the period January to 31 March 2026.

Condition	Number
Primary immunodeficiency (PID)	*
Secondary immunodeficiency (SID)	27
Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)	5

FOI.18943

1. - 4. The UHB regrets to inform you that it does not hold the information requested. UHB patients that require Haemophilia treatment are seen and treated by Cardiff and Vale University Health Board (C&VUHB).

Therefore, we recommend that you redirect this part of your request to the Freedom of Information Team at C&VUHB, who may be able to help you further. Their contact details are as follows:

FOI.Requests@wales.nhs.uk

5. The UHB provides within the table below, the total usage of Prothrombin Complex Concentrate (PCC) products listed, in International Units (IUs), during the 2025/26 financial year.

Product	IU
Prothromplex	0
Beriplex	0
Octaplex	539,500

6. An exemption under Section 12 of the FoIA has been applied.