

## Freedom of Information Request: Our Reference CTMUHB\_498\_23

### You asked:

I have a freedom of information request about rare inflammatory disorders. Could you please answer the following questions:

**Q1. In the past 12 months, how many patients have been admitted as inpatients for each of the following conditions\* (primary or secondary diagnosis)?**

- **Adult Onset Stills Disease (AOSD) – ICD10 code M06.1**
- **Juvenile Arthritis with Systemic Onset (SJIA) – ICD10 code M08.2**
- **Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumor Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonte Kinase Deficiency (MKD) – ICD10 code E85.0**
- **Cryopyrin-associated Periodic Syndromes (CAPS) – ICD10 code not available**

**\*In case you do not treat any condition, please provide the name of the trust you refer these patients to.**

Please see the information provided below for the date period 01/11/2023 – 31/10/2023.

Noting the following:

- Patients were admitted as inpatients at Cwm Taf Morgannwg University Health Board.
- Patient may also belong to another University Health Board area.
- Where data is reliant on clinical coding, this traditionally has a completion timeline of three months in arrears – therefore the data will be incomplete.
- Patients may have been admitted with more than one condition.
- Where the figures are less than 5, the exact figures have been withheld due to the low numbers involved.

Where numbers are low we have considered that there is the potential for the individuals to be identified from the information provided, when considered with other information that may also be in the public domain. Also, responses under the Freedom of Information Act are made available to the public at large. The data is classed as personal data as defined under the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute as unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This exemption is absolute and therefore there is no requirement to apply the public interest test.

- **Adult Onset Stills Disease (AOSD) – Less than 5.**
- **Juvenile Arthritis with Systemic Onset (SJIA) – 0**
- **Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumor Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonte Kinase Deficiency (MKD) – Less than 5**
- **Cryopyrin-associated Periodic Syndromes (CAPS) – 0**

**Q2. How many patients has your trust/health board treated with Anakinra (Kineret) in the past 12 months, for each of the following:**

- Any medical condition
- Rheumatoid Arthritis
- Adult Onset Stills Disease (AOSD)
- Juvenile Arthritis with Systemic Onset (SJIA)
- Periodic Fever Syndromes (FMF, TRAPS or MKD)
- Cryoprin-associated Periodic Syndromes (CAPS)

**Q3. How many patients has your trust/health board treated with Canakinumab (Ilaris) in the past 12 months, for each of the following:**

- Any medical condition
- Adult Onset Stills Disease (AOSD)
- Juvenile Arthritis with Systemic Onset (SJIA)
- Periodic Fever Syndromes (FMF, TRAPS or MKD)
- Cryoprin-associated Periodic Syndromes (CAPS)

**Q4. How many patients has your trust/health board treated with Tocilizumab in the past 12 months, for each of the following:**

- Any medical condition
- Adult Onset Stills Disease (AOSD)
- Juvenile Arthritis with Systemic Onset (SJIA)
- Periodic Fever Syndromes (FMF, TRAPS or MKD)
- Cryoprin-associated Periodic Syndromes (CAPS)

**Q5. How many patients has your trust/health board treated with Etanercept in the past 12 months, for each of the following:**

- Any medical condition
- Adult Onset Stills Disease (AOSD)
- Juvenile Arthritis with Systemic Onset (SJIA)
- Periodic Fever Syndromes (FMF, TRAPS or MKD)
- Cryoprin-associated Periodic Syndromes (CAPS)

Q2 – 5. Please find below a table populated with the data Medicines Management are able to provide at this current time (number of patients for any medical condition). The period the data relates to 1<sup>st</sup> November 22 to 31<sup>st</sup> October 23, the last 12 months as requested. Unfortunately, we are unable to provide patient numbers by condition because our Pharmacy Electronic Dispensing System does not record this information.

This information would be recorded within an individual patient's health record as part of their ongoing care. To provide you with this data, would require a manual trawl and significantly exceed the 18 hours time and £450 cost limit set out within Section 12 of the Freedom of Information Act.

Number of Patients for any medical condition		
Question Number	Medicine	Number of Patients
Q2.	Anakinra	**

Q3	Canakinumab	0
Q4	Tocilizumab	148
Q5	Etanercept	392

Where the figures are less than 5, this has been denoted by \*\*. The exact figures have been withheld due to the low numbers involved.

Where numbers are low we have considered that there is the potential for the individuals to be identified from the information provided, when considered with other information that may also be in the public domain. Also, responses under the Freedom of Information Act are made available to the public at large. The data is classed as personal data as defined under the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute as unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This exemption is absolute and therefore there is no requirement to apply the public interest test.