

Freedom of Information Act 2000 - Request Reference FoI/23/537

Rare Inflammatory Disorders

Information Requested:

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 Melvonnate 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.

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)
- Cryopyrin-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)
- Cryopyrin-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)
- Cryopyrin-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)

Response Details:

In response to Q1:

- Adult Onset Stills Disease (AOSD): 3
- Juvenile Arthritis with Systemic Onset (SJIA): 1
- Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumor Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonnate Kinase Deficiency (MKD): 2
- Cryoprin-associated Periodic Syndromes (CAPS): *

*In completing a search for the information requested, Cardiff and Vale University Health Board (the UHB) has confirmed that this information is not centrally recorded or collated. To retrieve the information requested would require a manual search through individual records and the UHB considers that this would exceed the limit set within regulations for responding to a request. The UHB has therefore relied upon the section 12 exemption ('Exemption where cost of compliance exceeds appropriate limit') of the Freedom of Information Act 2000 and is refusing your request.

The UHB has estimated that to complete the work needed to respond to this request would exceed the time limit as set within regulations to respond to a Freedom of Information Act request. Under the Act there is an allowance of two and a half days, or 18 hours, to comply with a request and the cost limit set within the Fees Regulations for this amount of work (18 hours) is £450 for the UHB. The Fees Regulations specify that the cost of complying with a request must be calculated at the rate of £25 per hour.

In response to Q2—Q5:

Please note that the UHB cannot provide condition-specific data. However, we have been able to compile the below figures which represent treatment for *any medical condition*.

Q2. 14

Q3. 1

Q4. 168

Q5. 273