

FOI1984

28/11/23

FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

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**
- **Cryoprin-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.

Response 1: Please see attached document for response.

** The Trust has a legal duty to protect patient confidentiality, in line with this duty the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves. In addition the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

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)**

Response 2:

Any medical condition	Data not held by pharmacy
Rheumatoid Arthritis	0
Adult Onset Stills Disease (AOSD)	5
Juvenile Arthritis with Systemic Onset (SJIA)	0

Periodic Fever Syndromes (FMF, TRAPS or MKD)	<5 **
Cryoprin-associated Periodic Syndromes (CAPS)	0

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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)

Response 3:

Any medical condition	0
Adult Onset Stills Disease (AOSD)	0
Juvenile Arthritis with Systemic Onset (SJIA)	0
Periodic Fever Syndromes (FMF, TRAPS or MKD)	0
Cryoprin-associated Periodic Syndromes (CAPS)	0

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)

Response 4:

Any medical condition	Data not held by pharmacy
Adult Onset Stills Disease (AOSD)	0
Juvenile Arthritis with Systemic Onset (SJIA)	0

Periodic Fever Syndromes (FMF, TRAPS or MKD)	0
Cryoprin-associated Periodic Syndromes (CAPS)	0

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 5:

Current patients

Any medical condition	193
Adult Onset Stills Disease (AOSD)	0
Juvenile Arthritis with Systemic Onset (SJIA)	0
Periodic Fever Syndromes (FMF, TRAPS or MKD)	0
Cryoprin-associated Periodic Syndromes (CAPS)	0

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