

Our Ref: 570/2023
November 2023

Re: Your request made under the Freedom of Information Act 2000

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 - **0**
- Juvenile Arthritis with Systemic Onset (SJIA) – ICD10 code M08.2 - **0**
- Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumor Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonte Kinase Deficiency (MKD) – ICD10 code E85.0

*** number too low to provide and therefore suppressed as per FOI rules.**

- 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.

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)

- **Our pharmacy system doesn't store diagnosis data, so we're unable to determine this against the prescribed treatment. To ascertain this data, the Trust would need to perform an audit of each individual patient record, which wouldn't be achievable within the s.12 timescale of the Freedom of Information Act 2000.**



**Doncaster and Bassetlaw
Teaching Hospitals**
NHS Foundation Trust

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