

Ref: FOI/GS/ID 8573

Please reply to:
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Freedom of Information Act 2000

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to Rare Diseases.

You asked: All questions are shown as received by the Trust.

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

- a. Adult Onset Stills Disease (AOSD) – ICD10 code M06.1*
- b. Juvenile Arthritis with Systemic Onset (SJIA) – ICD10 code M08.2*
- c. Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumor Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonte Kinase Deficiency (MKD) – ICD10 code E85.0*
- d. 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:

- a. Any medical condition*
- b. Rheumatoid Arthritis*
- c. Adult Onset Stills Disease (AOSD)*
- d. Juvenile Arthritis with Systemic Onset (SJIA)*
- e. Periodic Fever Syndromes (FMF, TRAPS or MKD)*
- f. 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:

- a. Any medical condition*
- b. Adult Onset Stills Disease (AOSD)*
- c. Juvenile Arthritis with Systemic Onset (SJIA)*

d. *Periodic Fever Syndromes (FMF, TRAPS or MKD)*

e. *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:

a. *Any medical condition*

b. *Adult Onset Stills Disease (AOSD)*

c. *Juvenile Arthritis with Systemic Onset (SJIA)*

d. *Periodic Fever Syndromes (FMF, TRAPS or MKD)*

e. *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:

a. *Any medical condition*

b. *Adult Onset Stills Disease (AOSD)*

c. *Juvenile Arthritis with Systemic Onset (SJIA)*

d. *Periodic Fever Syndromes (FMF, TRAPS or MKD)*

e. *Cryoprin-associated Periodic Syndromes (CAPS)*

Trust response:

Q1 Please note this is the number of patients and not the number of spells.

Diagnosis Code	E850	M061	M082	Grand Total
Number of Patients	6	7	6	19

d. We are unable to search for this without the ICD10 code.

Q2, Q4 and Q5. Under Section 21 of the Act we are not required to provide information in response to a request if the information is already reasonably accessible to you. The information you requested is available from the trust website using the following link/s: <https://www.mtw.nhs.uk/freedom-of-information/recent-foiresponses/> the link should take you to the Data to Support FOI FAQ's page where you need to click on the Pharmacy dropdown. If the document does not open please copy and paste the link into your browser.

Alternatively, from our website home page, click the Freedom of Information Tab, then the Data to Support FOI FAQ's tab and then the Pharmacy dropdown at the bottom of the page where you will find all the information.

This information is updated on a regular basis and is exempt under Section 22 of the Act.

Q3. No usage of Canakinumab.