

Executive Corridor
Darlington Memorial Hospital
Hollyhurst Road
Darlington
DL3 6HX
Switchboard Tel: 01325 38 0100
Foundation Trust Office: 01325 74 3625
Corporate Records Office: 01325 74 3700

Request for Information Reference: 10.23.52

FOI Direct line: 01325 743700
Email: cdda-tr.cddftfoi@nhs.net

Email only

13th November 2023

Dear

Freedom of Information Act 2000 – Request for Information

Thank you for submitting a request for information which we received on 17th October 2023 in relation to County Durham and Darlington NHS Foundation Trust (the Trust). Your request has been processed under the provisions of the Freedom of Information Act 2000 and I am now able to provide you with a response.

Your request was in relation to Rare Diseases and I am providing the following information in response to your specific questions:

1. 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**

One

- **Juvenile Arthritis with Systemic Onset (SJIA) – ICD10 code M08.2**

5

- **Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumor Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonte Kinase Deficiency (MKD) – ICD10 code E85.0**

Zero

- **Cryoprin-associated Periodic Syndromes (CAPS) – ICD10 code not available**

The Trust are not able to answer this question as there is no valid ICD10 code for this condition.

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

2. 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 - 2
- Rheumatoid Arthritis - 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

3. 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 - 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

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

- Any medical condition - 163
- 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

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

- Any medical condition - 527
- 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

In line with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log on the Trust's website. However please be assured that we anonymise all responses prior to adding them to the disclosure log.

I hope that this response has provided you with the information you had requested. If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me by telephone or in writing. If however, you are dissatisfied with the way in which your request has been handled and would like an internal review, you will need to contact me in writing at the above address or via cdda-tr.cddftfoi@nhs.

If you remain dissatisfied with our response following an internal review you have the right to appeal to The Information Commissioner at Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF. More information is available on their website; www.ico.gov.uk.

Yours sincerely

Corporate Records and Freedom of Information Facilitator