



Bwrdd Iechyd  
Addysgu Powys  
Powys Teaching  
Health Board

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Powys LD3 0LY  
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Our ref: IG/FOI/23.R.362

20 October 2023

Sent via email to: [REDACTED] k

Dear [REDACTED]

## Request under the Freedom of Information Act 2000

I write further to your request for information which was received on 17 October 2023, to confirm, in accordance with S.1(1)(a) of the Freedom of Information Act 2000, that Powys Teaching Health Board (PTHB) does not hold the information that you require.

For ease of reference your request is set out below and our response follows:

### Your Freedom of Information (FOI) Request:

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
- 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
- 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)

Pencadlys  
Tŷ Glasbury, Ysbyty Bronllys,  
Aberhonddu, Powys LD3 0LU  
Ffôn: 01874 711661



Headquarters  
Glasbury House, Bronllys Hospital  
Brecon, Powys LD3 0LU  
Tel: 01874 711661



- 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)

Powys Response:

Q1 Powys Teaching Health Board does not have any specialist departments which admit patients for treatment of the listed conditions. Our patients are treated by several providers outside of Powys, in both Welsh health boards and English provider organisations. We therefore recommend that our providers are approached directly and have listed their contact details in the tables below.

Q2-Q5 Powys Teaching Health Board does not have any specialist departments which treat patients with the listed conditions. Our patients are referred to and treated by several providers outside of Powys, in both Welsh health boards and English provider organisations. We therefore recommend that our providers are approached directly and have listed their contact details in the tables below.

<b>Health Board/Organisation (Wales)</b>	<b>FOI Contact Details</b>
Aneurin Bevan University Health Board	<a href="mailto:FOI.ABB@wales.nhs.uk">FOI.ABB@wales.nhs.uk</a>
Betsi Cadwaladr University Health	<a href="mailto:bcu.foi@wales.nhs.uk">bcu.foi@wales.nhs.uk</a>

Board	
Cardiff & Vale University Health Board	<a href="mailto:FOI.Requests@wales.nhs.uk">FOI.Requests@wales.nhs.uk</a>
Cwm Taf Morgannwg University Health Board	<a href="mailto:Freedomofinformation@wales.nhs.uk">Freedomofinformation@wales.nhs.uk</a>
Hywel Dda University Health Board	<a href="mailto:FOI.hyweldda@wales.nhs.uk">FOI.hyweldda@wales.nhs.uk</a>
Swansea Bay University Health Board	<a href="mailto:FOIA.Requests@wales.nhs.uk">FOIA.Requests@wales.nhs.uk</a>
Velindre University Health Board	<a href="mailto:Foi.vunhst@wales.nhs.uk">Foi.vunhst@wales.nhs.uk</a>

<b>NHS Provider (England)</b>	<b>FOI Contact Details</b>
Gloucester Hospitals NHS Foundation Trust	<a href="mailto:ghn-tr.foi@nhs.net">ghn-tr.foi@nhs.net</a>
Midlands Partnership NHS Foundation Trust	<a href="mailto:FOI@mpft.nhs.uk">FOI@mpft.nhs.uk</a>
Sandwell and West Birmingham NHS Trust	<a href="mailto:swb-tr.SWBH-GM-FOIRequests@nhs.net">swb-tr.SWBH-GM-FOIRequests@nhs.net</a>
Shrewsbury and Telford Hospital NHS Trust	<a href="https://www.sath.nhs.uk/about-us/freedom-of-information/make-an-enquiry/">https://www.sath.nhs.uk/about-us/freedom-of-information/make-an-enquiry/</a>
The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust	<a href="mailto:rjah.foi@nhs.net">rjah.foi@nhs.net</a>
The Royal Wolverhampton NHS Trust	<a href="mailto:rwh-tr.foi@nhs.net">rwh-tr.foi@nhs.net</a>
Worcestershire Acute Hospitals NHS Trust	<a href="mailto:wah-tr.FOI@nhs.net">wah-tr.FOI@nhs.net</a>
Wye Valley NHS Trust	<a href="mailto:Freedom.information@WVT.nhs.uk">Freedom.information@WVT.nhs.uk</a>

Should you need any further assistance, please do not hesitate to contact me at the address below.

If you are dissatisfied, with the way your request has been dealt with by PTHB, you have the right to request a review in which case you should write to:

Chief Executive  
 Powys Teaching Health Board Headquarters  
 Glasbury House  
 Bronllys Hospital  
 Bronllys  
 Brecon  
 Powys LD3 0LY

If you are still dissatisfied at the end of the review, you may complain to the Information Commissioner, who can be contacted at the following address:

Information Commissioner's Office - Wales  
 2<sup>nd</sup> Floor,  
 Churchill House,  
 Churchill Way,  
 Cardiff, CF10 2HH  
 Tel: 029 2067 8400 Fax 029 2067 8399

[www.ico.org.uk](http://www.ico.org.uk)

[twitter.com/iconews](https://twitter.com/iconews)

Rydym yn croesawu derbyn gohebiaeth yng Nghymraeg. Byddwn yn ateb y fath ohebiaeth yng Nghymraeg ac ni fydd hyn yn arwain at oedi. We welcome receiving correspondence in Welsh. We will reply to such correspondence in Welsh and this will not lead to a delay.

Yours sincerely

A handwritten signature in black ink that reads "KLWright". The signature is written in a cursive style with a horizontal line underneath the name.

**Kate Wright**  
**Medical Director**