

Trust Headquarters
Russell's Hall Hospital
Dudley
West Midlands
DY1 2HQ

Ref: FOI-012025-0001377

Date: 4.2.25

Address / Email:

Dear

Request Under Freedom of Information Act 2000

Thank you for requesting information under the Freedom of Information Act 2000.

1. An estimate of the number of patients with HAE in your trust - 24
2. Names of the Clinical Lead Responsible for HAE and any associated Team Members
- Dr M Bhole, Consultant Immunologist, Dr C Tsakona, Locum Consultant Immunologist and Mrs A Thomas, Immunology CNS
3. Contact Information for the Lead/Department or secretary (phone or email) –
dgft.immunologyoffice@nhs.net
4. How are patients with HAE managed?
– Appropriate investigations to confirm diagnosis (including genetic tests where indicated) followed by discussion regarding on-demand and/or in-hospital management of acute attacks with verbal and written information and long term prophylaxis as and when indicated as per severity and frequency of symptoms
5. What does the care pathway look like for patients with HAE?
- Referrals accepted from Primary or Secondary care Physicians, seen in Immunology outpatient clinics, investigated to confirm diagnosis and appropriate management plan put in place for management of acute episodes and short term and long-term prophylaxis as and when needed – GP, patient/parent and any relevant secondary care teams kept informed with clinic correspondence.
6. What does the care pathway look like for patients with HAE?
– same as point 5
7. What are the main challenges when managing patients with HAE?
– awareness of this rare primary immunodeficiency condition amongst Primary care clinicians and front line healthcare professionals (including ambulance care teams and A&E staff)
8. Other than the Immunology Department, are there any other departments or services that might be involved in the care of patients with HAE?
- Ambulance services, A&E teams during acute episodes and any surgical, obstetric or dental teams as and when needed

9. Do you have any insights into the status of the UK Rare Disease Framework, or could you share contact details of someone that would?
 - Aware of this framework and try to incorporate the principles of the framework in our clinical practice as much as possible
10. Any other relevant feedback?
 - The department participates actively in regional and national network meetings and contributes to national audits in relation to this condition

If you are dissatisfied with our response, you have the right to appeal in line with guidance from the Information Commissioner. In the first instance you may contact the Information Governance Manager of the Trust.

Information Governance Manager
Trust Headquarters
Russell's Hall Hospital
Dudley
West Midlands
DY1 2HQ
Email: dgft.dpo@nhs.net

Should you disagree with the contents of our response to your appeal, you have the right to appeal to the Information Commissioners Office at.

Information Commissioners Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
Tel: 0303 123 1113
www.ico.org.uk

If you require further clarification, please do not hesitate to contact us.

Yours sincerely

Freedom of Information Team
The Dudley Group NHS Foundation Trust