

Freedom of Information Request

Ref: 25-066

13 February 2025

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we do hold the information you are requesting

Under the Freedom of Information Act 2000, I am requesting information about the management of Hereditary Angioedema within you Hospital and would value feedback on any of the points below:

1. An estimate of the number of patients with HAE in your trust.

Approximately 46

2. Names of the Clinical Lead Responsible for HAE and any associated Team Members

Dr Jolanta Bernatoniene, HAE lead

Florence Manyika – Clinical Nurse Specialist Lead

Consultants - Dr Marion Roderick, Dr Anu Goenka and Dr Stefania Vergnano.

3. Contact Information for the Lead/Department or secretary (phone or email).

paedidimmunologyadmin@uhbw.nhs.uk

4. How are patients with HAE managed?

For management of acute attacks we use on demand treatments and short or long term prophylaxis medication. Patients have regular follow ups in the paediatrics Immunology Department clinic (every 3-6 months as needed), in Bristol or regional clinics

5. What does the care pathway look like for patients with HAE?

For management of acute attacks we use on demand treatments and short or long term prophylaxis medication. Patients have regular follow ups in the paediatrics Immunology Department clinic (every 3-6 months as needed), in Bristol or regional clinics

6. What does the care pathway look like for patients with HAE?

Duplicate question – please see the response to q4 and 5.

7. What are the main challenges when managing patients with HAE?

Making sure the patients and the families are aware of how to manage acute episodes, when to escalate and liaise with health care professionals/attend the Emergency Department. The main challenges for children are limited treatment options/oral formulations. Most of the medications are currently administered parenterally which can be difficult, especially for children under the age of six.

8. Other than the Immunology Department, are there any other departments or services that might be involved in the care of patients with HAE?

Emergency Department

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?

We are aware of the framework. No.

10. Any other relevant feedback?

We underwent the QPIDS accreditation process for the regional paediatric immunology and our service received the QPIDS accreditation in May 2021. We were the third paediatric immunology service ever accredited at that time in the UK.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Data Protection Officer
University Hospitals Bristol and Weston NHS Foundation Trust
Trust Headquarters
Marlborough Street
Bristol
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because

information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

Freedom of Information Team
University Hospitals Bristol and Weston NHS Foundation Trust