

01 July 2021

Our Ref: RFI 38026

Dear

**Freedom of Information Act 2000
Information in relation to Hereditary Angioedema (HAE)**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to above which you requested on 2 March 2021. Please accept our sincere apologies on the delay in responding to you. Thank you for your patience.

A response to each of the questions raised has been provided by the Hospital Services Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital (informationgovernance@setrust.hscni.net) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

Rebecca Manning
Information Governance Assistant

Q1. In the past 6 months [latest 6 months available] how many patients have received the following treatments [for any disease]:

- **Berinert (Human C1-esterase inhibitor)**
- **Cinryze (Human C1-esterase inhibitor)**
- **Takzyro (Lanadelumab)**
- **Ruconest (Recombinant human C1-esterase inhibitor)**
- **Firazyr (Icatibant injection)**

A1. There have been no patients treated in the Trust, for any disease, with the above listed treatments.

Q2. In the past 6 months [latest 6 months available] how many patients have received the following immunoglobulin treatments [for any disease]:

A2. Please see Table 1.

Table 1

Treatments/Medication	Number of Patients Treated
Cuvitru	Nil
Gammanorm	Nil
Gamunex	<5
Hizentra	Nil
Hyqvia	Nil
Kiovig	Nil
Octagam	6
Privigen	30
Subgam	Nil

NB. You will note that some of the numbers have been masked and this is due to small numbers within a small geographical area.

Q3. In the past 6 months, how many patients attended A&E for Hereditary Angioedema (ICD10 code: D84.1) or Angioedema (ICD10 code: T78.3)?

Of these patients, how many were treated with the following products:

- **Berinert (Human C1-esterase inhibitor)**
- **Cinryze (Human C1-esterase inhibitor)**
- **Ruconest (Recombinant human C1-esterase inhibitor)**
- **Firazyr (Icatibant injection)**

A3. There were 4 patients admitted to Accident & Emergency within the past 6 months with diagnosis of either Hereditary Angiodema or Angiodema, however none of these patients were treated with the above listed treatments.