

FOI REF: 26/355

30th June 2026

Eastbourne District General Hospital

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Further to your recent request for information made under the Freedom of Information Act (FOIA) 2000, I now set out our answers to your specific questions, and any clarifications sought and provided, as follows:

- 1) How many new patients have been diagnosed with wild type Transthyretin Amyloid Cardiomyopathy (ATTR-CM) in your Trust in the last 4 months?**

Please note that the Trust's coding system does not differentiate between wild type Transthyretin Amyloid Cardiomyopathy (ATTR-CM) and hereditary Transthyretin Amyloid Polyneuropathy (ATTR-PN).

The number of patients with a diagnosis of ATTR discharged 1st January 2026 to 30th April 2026 is 10.

- 2) How many new patients have been diagnosed with hereditary Transthyretin Amyloid Polyneuropathy (ATTR-PN) in your Trust in the last 4 months?**

Please see the response to question 1.

- 3) What is the total number of patients with wild type Transthyretin Amyloid Cardiomyopathy (ATTR-CM) being treated in your Trust?**

Clarification was sought in respect of questions 3 and 4, asking you to confirm the date range you would like us to pull the data for, and confirmation was received that you require the following:

For those questions, please report total patient numbers at present time.

Please see the responses to questions 1, 5 and 6.

- 4) What is the total number of patients with hereditary Transthyretin Amyloid Polyneuropathy (ATTR-PN) being treated in your Trust?**

Please see the responses to questions 1, 5 and 6.

- 5) **Of the newly diagnosed wild type ATTR-CM patients, how many were initiated with the following treatments:**
- a) **Vutrisiran**
 - b) **Tafamidis 61mg**
 - c) **Acoramidis**
 - d) **Enrolled in a clinical study**

Please note that the Trust's coding system does not differentiate between wild type Transthyretin Amyloid Cardiomyopathy (ATTR-CM) and hereditary Transthyretin Amyloid Polyneuropathy (ATTR-PN). However, the Trust is able to confirm that no patients with a diagnosis of ATTR received any of the treatments listed above between 1st January 2026 and 30th April 2026, and no ATTR patients have been enrolled in a clinical study.

- 6) **Of the newly diagnosed ATTR-PN patients, how many were initiated with the following treatments:**
- a) **Vutrisiran**
 - b) **Eplontersen**
 - c) **Enrolled in a clinical study**

Please note that the Trust's coding system does not differentiate between wild type Transthyretin Amyloid Cardiomyopathy (ATTR-CM) and hereditary Transthyretin Amyloid Polyneuropathy (ATTR-PN). However, the Trust is able to confirm that no patients with a diagnosis of ATTR received any of the treatments listed above between 1st January 2026 and 30th April 2026, and no ATTR patients have been enrolled in a clinical study.

- 7) **What is your Trust's protocol for confirming diagnosis of ATTR patients? Is diagnosis confirmed by your Trust or the National Amyloidosis Centre (NAC)?**

East Sussex Healthcare NHS Trust screens patients initially, but diagnosis is confirmed by the National Amyloidosis Centre. Their contact details are as follows:

By email: foirequest@ucl.ac.uk

- 8) **Of the diagnosed patients, how many had their diagnosis made/confirmed:**
- a) **In your Trust**
 - b) **By the National Amyloidosis Centre (NAC) London or Midlands**

Please see the response to question 7.

9) How many patients have been confirmed for treatment initiation either:

- a) Virtually**
- b) In person**

[Please see the response to question 7.](#)

I trust this information is helpful in its detail or explanation however, if you are dissatisfied with the response, then you have the right to request an internal review. If you wish to seek an internal review, please write to the Freedom of Information Team at esh-tr.foi@nhs.net quoting the above FOI reference number, within 40 working days. Please note the Trust is not obliged to accept a request for an internal review after this time period.

Yours faithfully

Freedom of Information (FOI) Team
East Sussex Healthcare NHS Trust
0300 131 4716
Core Hours of Business: Monday to Friday 9.00am to 4.00pm