

22 June 2026

FOI Request: Transthyretin Amyloidosis (ATTR) Information, May-26

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

Number of patients sent for testing in the last four months:

Trust	Belfast	South Eastern	Southern	Northern	Western
Number Tested	<5	<5	<5	6	<5

Results pending on 10 patients, <5 patients negative for molecular testing which is performed by NAC.

Some figures have been withheld and replaced with less than five (<5). This is because disclosure of small numbers may risk identifying individuals. The information is therefore exempt under Section 40(2) of the Freedom of Information Act 2000 - Personal Information relating to a third party. Its release would contravene the data protection principles set out in the UK GDPR.

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

No new patients have been molecularly diagnosed to date in the last four months.

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

In accordance with Section 1(1)(a) of the Freedom of Information Act 2000, Belfast Trust can confirm that no further information is held in relation to this request as we do not have systems in place that would capture this data.

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

There are zero patients with hereditary Transthyretin Amyloid Polyneuropathy (ATTR-PN) being treated in Belfast Trust.

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- 5. Of the newly diagnosed wild type ATTR-CM patients, how many were initiated with the following treatments**
- 1. Vutrisiran**
 - 2. Tafamidis 61mg**
 - 3. Acoramidis**
 - 4. Enrolled in a clinical study**

In accordance with Section 1(1)(a) of the Freedom of Information Act 2000, Belfast Trust can confirm that no further information is held in relation to this request as we do not have systems in place that would capture this data.

- 6. Of the newly diagnosed ATTR-PN patients, how many were initiated with the following treatments**
- 1. Vutrisiran**
 - 2. Eplontersen**
 - 3. Enrolled in a clinical study**

In accordance with Section 1(1)(a) of the Freedom of Information Act 2000, Belfast Trust can confirm that no further information is held in relation to this request as we do not have systems in place that would capture this data.

- 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)?**

Diagnosis of Transthyretin Amyloidosis (ATTR) requiring molecular confirmation is undertaken by the National Amyloidosis Centre (NAC). The Belfast Trust refers patients for specialist testing and confirmation, with NAC providing definitive diagnostic confirmation.

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

In accordance with Section 1(1)(a) of the Freedom of Information Act 2000, Belfast Trust can confirm that no further information is held in relation to this request as we do not have systems in place that would capture this data.

- 9. How many patients have been confirmed for treatment initiation either**
- 1. Virtually**
 - 2. In person**

In accordance with Section 1(1)(a) of the Freedom of Information Act 2000, Belfast Trust can confirm that no further information is held in relation to this request as we do not have systems in place that would capture this data.