

Reference:	FOI.20465.26
Subject:	Transthyretin Amyloidosis (ATTR)
Date of Request:	18 May 2026

Requested:

1. How many new patients have been diagnosed with wild type Transthyretin Amyloid Cardiomyopathy (ATTR-CM) in your Trust in the last 4 months?
2. How many new patients have been diagnosed with hereditary Transthyretin Amyloid Polyneuropathy (ATTR-PN) in your Trust in the last 4 months?
3. What is the total number of patients with wild type Transthyretin Amyloid Cardiomyopathy (ATTR-CM) being treated in your Trust?
4. What is the total number of patients with hereditary Transthyretin Amyloid Polyneuropathy (ATTR-PN) being treated in your Trust?
5. Of the newly diagnosed wild type ATTR-CM patients, how many were initiated with the following treatments
 - Vutrisiran
 - Tafamidis 61mg
 - Acoramidis
 - Enrolled in a clinical study
6. Of the newly diagnosed ATTR-PN patients, how many were initiated with the following treatments
 - Vutrisiran
 - Eplontersen
 - 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)?
8. Of the diagnosed patients, how many had their diagnosis made/confirmed
 - In your Trust
 - By the National Amyloidosis Centre (NAC) London or Midlands
9. How many patients have been confirmed for treatment initiation either
 - Virtually
 - In person

Response:

Hywel Dda University Health Board (UHB) does not hold all of the information requested, as ATTR patients are treated at the National Amyloidosis Centre in the Royal Free London NHS Foundation Trust, the UK's centrally commissioned national referral centre for Amyloidosis.

We therefore recommend that you redirect questions 3 to 9 your request to the Freedom of Information Team in the Royal Free London NHS Foundation Trust. The contact details are as follows:

rf-tr.foi@nhs.net or alternatively, you can contact: The Freedom of Information Department, Royal Free Hospital, Pond Street, London, NW3 2QG.

However, the UHB can confirm that it has undertaken a search of its Welsh Patient Administration System (WPAS) and it has not identified any patients diagnosed with ATTR Cardiomyopathy or ATTR Polyneuropathy, during the period 1 January to 30 April 2026.