Freedom of Information Request: Our Reference CTMUHB_296_26

You asked:

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

   We can confirm that the Health Board does not centrally or routinely record this information.

   Information relating to ATTR conditions (including ATTR-CM and ATTR-PN), associated diagnoses, and treatment initiation is not coded or recorded in a format that enables the Health Board to readily extract data to:

   - identify these patient cohorts,
   - distinguish between subtypes (e.g. wild type vs hereditary), or
   - report initiation by specific therapies (e.g. Vutrisiran, Tafamidis, Acoramidis, Eplontersen)

   without undertaking a manual review of individual patient records. Which we have estimated would significantly exceed the 18 hours time and £450 cost limit set out within Section 12 of the Freedom of Information Act. Therefore, we are unable to provide.

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 response to Q1.

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

   Please see response to Q1.

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

   Please see response to Q1.

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**

   Please see response to Q1.

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**

Please see response to Q1.

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

Patients suspected of having amyloidosis are typically referred to specialist services, and diagnosis is made in line with national and specialist pathways.

Diagnosis of ATTR conditions is not routinely confirmed solely within the Health Board. Patients are commonly referred to the National Amyloidosis Centre (NAC), which provides specialist diagnostic confirmation.

The Health Board supports local assessment and referral but relies on specialist centres for definitive diagnosis and typing.

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

Please see response to Q1.

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

Please see response to Q1.