

Freedom of Information Act 2000 - Request Reference Fol/21/370

Rare Diseases

Request Details

1. Within your trust, how many patients currently have a diagnosis for:
 - Fabry Disease ICD10 code (E75.21) **50**
 - Gaucher Disease (ICD10 code E75.22) **13**
 - MPS II (Hunter Syndrome) (ICD10 code E76.1) **0**

2. Of the patients above, how many patients have been newly diagnosed within the past 3 months for:
 - Fabry Disease ICD10 code (E75.21) **0**
 - Gaucher Disease (ICD10 code E75.22) **0**
 - MPS II (Hunter Syndrome) (ICD10 code E76.1) **0**

3. How many patients (including any patients whose treatment is on hold due to COVID-Shielding) are being treated at this point in time with:
 - Replagal (agalsidase alpha) **10**
 - Fabrazyme (algalsidase beta) **7**
 - Galafold (migalastat) **12**
 - VPRIV (velaglucerase alfa) *
 - Cerezyme (imiglucerase) *
 - Cerdelga (eliglustat) *
 - Zavesca (miglustat) **0**
 - Any other treatment for Fabry disease [please state which treatments] **0**
 - Any other treatment for Gaucher disease [please state which treatments] **0**

Please note that Section 40 of the Freedom of Information Act 2000 has been applied where information above has been replaced with an asterisk. Cardiff and Vale University Health Board (the UHB) will not provide these exact numbers due to the low numbers of individuals involved (5 or less). The UHB believes there is a potential risk of individuals being able to be identified, when considered with other information already available within the public domain, if this was disclosed. Therefore, the data is classed as personal data as defined under the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This exemption is absolute and therefore there is no requirement to apply the public interest test.

4. Can you please provide the split of patients being treated between homecare patients and hospital treated patients for the following two diseases?

Fabry Disease (ICD10 code (E75.21)

- Hospital treated Patients **0**
- Homecare Patients **23**

Gaucher Disease (ICD10 code E75.22)

- Hospital treated Patients **0**
- Homecare Patients **11**

5. Do you have any Fabry Disease or Gaucher Disease patients on clinical trials? If so can you please advise how many patients and the name of the trial for each of the following two diseases?

- Fabry Disease ICD10 code (E75.21) **0**
- Gaucher Disease (ICD10 code E75.22) **0**