Freedom of Information Act 2000 - Request Reference FoI/20/296
Inherited Metabolic Disorders

Request details

Hello Cardiff and Vale University Health Board,

We have a freedom of information request related to the incidence and treatment of some inherited metabolic disorders. Could you please provide answers to the following four questions?

1. **Within your trust, how many patients currently have a diagnosis for**

Fabry Disease: **51 patients**
Gaucher Disease: **12 patients**
MPS II (Hunter Syndrome): **0 patients**

2. **Of the patients above, how many have been newly diagnosed within the past 3 months for**

Fabry Disease: **1 patient**
Gaucher Disease: **0 patients**
MPS II (Hunter Syndrome): **0 patients**

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): **8 patients**
Fabrazyme (agalsidase beta): **6 patients**
Galafold (migalastat): **10 patients**
VPRIV (velaglucerase alfa)**: 2 patients**
Cerezyme (imiglucerase): **6 patients**
Cerdelga (eliglustat): **4 patients**
Zavesca (miglustat): **0 patients**
Any other treatment for Fabry disease [please state which treatments]
Any other treatment for Gaucher disease [please state which treatments]

4. **Of the patients being treated for Fabry disease can you please provide the numbers of patients being treated through homecare?**

All of our Fabry patients on ERT/SRT receive their treatment via homecare.