

Freedom of Information request 014951

12/8/19

I am writing to you today to formally request information relating to the diagnosis and treatment of Homozygous Familial Hypercholesterolaemia (HoFH) at The Dudley Group NHS Foundation Trust.

Specifically, I am after the following information:

1. Does The Dudley Group NHS Foundation Trust diagnose patients with Homozygous Familial Hypercholesterolaemia (HoFH)? Y

a. If yes, does your trust diagnose adult patients, paediatric patients or both? - BOTH

b. How many patients in the last calendar year have you diagnosed with this condition? Please provide where available (and applicable) a breakdown by Adult and/or Paediatric Patients. - None with homozygous FH

c. Which of the following tests/diagnostic procedures do you use at The Dudley Group NHS Foundation Trust in relation to the diagnostics of HoFH? For these tests, which ones are you able to carry out "in house"? Of those carried out elsewhere, where are patients referred to have the testing carried out? For answers please use table below.

Test name	Test used for HoFH diagnosis at Trust Y/N	Test carried out by trust In-house for diagnosis of HoFH Y/N	Details of referral organisation/location for those tests that cannot be carried out by the trust
Cascade Genetic/DNA Tests	Y	N	Bristol Genetics Lab
Dutch Lipid Clinic Network (DLCN) criteria	Y	Y	Carried out at Trust
Simon Broome Diagnostic Criteria	Y	Y	Carried out at Trust
Family History	Y	Y	Carried out at Trust
Cholesterol/LDL Blood Testing	Y	Y	Carried out at Trust
Other (please specify)			

2. Does The Dudley Group NHS Foundation Trust treat patients with Homozygous Familial Hypercholesterolaemia (HoFH)? - Y

a. If no, please specify where patients diagnosed with HoFH are referred to for treatment. Please specify Trust/Organisation Name and Hospital Name where possible.

b. If yes, does your trust treat adult patients, paediatric patients or both? - BOTH

i. If your trust doesn't treat a subgroup (Adult or Paediatric), to which organisation are this sub group referred to for treatment? Please specify Trust/Organisation Name and Hospital Name where possible. N/A

c. How many patients in the last calendar year have received treatment for HoFH at The Dudley Group NHS Foundation Trust? Please provide where available (and applicable) a breakdown by Adult and/or Paediatric Patients. - As per NHS Digital rules the Trust does not publish numbers lower than 5 as this could lead to the identification of the persons involved. Exemption Section 40(2) of the Act is applied

d. For HoFH patients requiring Apheresis, are you able to carry out this procedure at The Dudley Group NHS Foundation Trust? - No

i. If no, to which organisation(s) do you refer patients to for Apheresis treatment and how many patients are referred to these sites?

Please list by trust name and hospital site where available, - Queen Elizabeth Hospital Birmingham

and where possible/applicable please breakdown patient referrals by Adult and Paediatric. - No referrals

ii. If yes, how many HoFH patients in the past calendar year have been treated by Apheresis by The Dudley Group NHS Foundation Trust? Please where possible (and applicable) provide with break down by Adult and Paediatric Patients. - N/A

I thank you for your time in reading my request, if you have any issues or queries then please do not hesitate to get in touch.