

Request for Information Reference: 07.19.61

Direct line: 01325 743700

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Email only

14 August 2019

### **Freedom of Information Act 2000 – Request for Information**

Thank you for your request for information received on 25 July 2019 in relation to the County Durham and Darlington NHS Foundation Trust (Trust). We are dealing with your request under the provisions of the Freedom of Information Act 2000.

You requested information regarding the Homozygous Familial Hypercholesterolaemia (HoFH). Specifically you requested information as follows:

***I am writing to you today to formally request information relating to the diagnosis and treatment of Homozygous Familial Hypercholesterolaemia (HoFH) at County Durham & Darlington NHS Foundation Trust. Specifically, I am after the following information:***

***1. Does County Durham & Darlington NHS Foundation Trust diagnose patients with Homozygous Familial Hypercholesterolaemia (HoFH)? Y/N***

Answer: Yes, but to date we have not had any positive diagnosis of homozygous FH. We continue to diagnose heterozygous FH from the genetic analysis forwarded by CDDFT; lipid services.

***a. If yes, does your Trust diagnose adult patients, paediatric patients or both?***

Answer: Adults only

***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.***

Answer: To date we have not had any Homozygous FH in our cohort of patients sent for genetic analysis.

**c. Which of the following tests/diagnostic procedures do you use at County Durham & Darlington 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.**

- i. Cascade Genetic/DNA Tests**
- ii. Dutch Lipid Clinic Network (DLCN) criteria**
- iii. Simon Broome diagnostic criteria**
- iv. Family History**
- v. Cholesterol/LDL Blood Testing**
- vi. Other (please specify details of name of test in the FOI return)**

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

**2. Does County Durham & Darlington NHS Foundation Trust treat patients with Homozygous Familial Hypercholesterolaemia (HoFH)? Y/N**

Answer: No – as we don't have any existing patients with HoFH

**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.**

Answer: No – as we don't have any existing patients with HoFH

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

Answer: Newcastle Lipid Services

**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.**

Answer: N/A

**c. How many patients in the last calendar year have received treatment for HoFH at County Durham & Darlington NHS Foundation Trust? Please provide where available (and applicable) a breakdown by Adult and/or Paediatric Patients.**

Answer: Nil as we do not have any patients with HoFH in our cohort at the current moment

**d. For HoFH patients requiring Apheresis, are you able to carry out this procedure at County Durham & Darlington NHS Foundation Trust? Y/N**

Answer: 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, and where possible/applicable please breakdown patient referrals by Adult and Paediatric.**

Answer: Referral will be made to Newcastle Lipid Services but to date we have no existing patients with HoFH

***ii. If yes, how many HoFH patients in the past calendar year have been treated by Apheresis by County Durham & Darlington NHS Foundation Trust?***

Answer: N/A

In line with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the County Durham and Darlington NHS Foundation Trust website.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the way your request for information has been handled, you can request a review by writing to:

The Chief Executive  
County Durham & Darlington NHS Foundation Trust  
Darlington Memorial Hospital  
Hollyhurst Road  
Darlington  
DL3 6HX

If, you remain dissatisfied with the handling of your request or complaint, you have a right to appeal to the Information Commissioner at:

The Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

Telephone: 0303 123 1113

Website: [www.ico.gov.uk](http://www.ico.gov.uk).

There is no charge for making an appeal.

Yours sincerely

**Joanna Tyrrell**  
**Freedom of Information Officer**