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Iechyd Cyhoeddus
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Public Health
Wales

Freedom of Information request to Public Health Wales

FOI Reference:

FOI 237

Date request received

25/07/2019

Date information is due to be sent

N/A

Information requested:

I am writing to you today to formally request information relating to the diagnosis and treatment of Homozygous Familial Hypercholesterolaemia (HoFH) at Public Health Wales.

Specifically, I am after the following information:

1. Does Public Health Wales diagnose patients with Homozygous Familial Hypercholesterolaemia (HoFH)? Y/N
 - a. If yes, does your trust diagnose adult patients, paediatric patients or 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.
 - c. Which of the following tests/diagnostic procedures do you use at Public Health Wales 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)

2. Does Public Health Wales treat patients with Homozygous Familial Hypercholesterolaemia (HoFH)? Y/N
 - 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?

- 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.
- c. How many patients in the last calendar year have received treatment for HoFH at Public Health Wales? Please provide where available (and applicable) a breakdown by Adult and/or Paediatric Patients.
- d. For HoFH patients requiring Apheresis, are you able to carry out this procedure at Public Health Wales? Y/N
 - 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.
 - ii. If yes, how many HoFH patients in the past calendar year have been treated by Apheresis by Public Health Wales? Please where possible (and applicable) provide with break down by Adult and Paediatric Patients.

Information provided for the answer:

Thank you for your email received 25 July 2019. I regret to inform you that we do not hold the information you requested.

May we recommend that you contact the following sources who may be able to help you with your enquiry:-

Abertawe Bro Morgannwg University Health Board

http://www.wales.nhs.uk/sitesplus/863/page/39302#Freedom_of_Information_Act_inquiries

Aneurin Bevan University Health Board

<http://www.wales.nhs.uk/sitesplus/866/page/39187>

Betsi Cadwaladr University Health Board

<http://www.wales.nhs.uk/sitesplus/861/page/39134>

Cardiff and Vale University Health Board

<http://www.cardiffandvaleuhb.wales.nhs.uk/freedom-of-information-new>

Cwm Taf University Health Board

<http://cwmtaf.wales/foi/>

Hywel Dda University Health Board

<http://www.wales.nhs.uk/sitesplus/862/page/52085>

Powys Teaching Health Board

<http://www.powysthb.wales.nhs.uk/freedom-of-information>

If you are unhappy with the service you have received in relation to your request and wish to make a complaint or request a review of the decision, you should write to the Corporate Complaints Manager, Public Health Wales NHS Trust, 3, Number 2, Capital Quarter, Tyndall Street, Cardiff, CF10 4BZ.

If you are not content with the outcome of your complaint or review, you may apply directly to the Information Commissioner for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by the Trust. The Information Commissioner can be contacted at:

Information Commissioner for Wales

2nd Floor
Churchill House
Churchill Way
Cardiff
CF10 2HH

Telephone: 029 2067 8400

Email: wales@ico.org.uk