NHS Tayside has now considered your request dated 25 July 2019.

Extract from Request

“I am writing to you today to formally request information relating to the diagnosis and treatment of Homozygous Familial Hypercholesterolaemia (HoFH) at NHS Tayside. Specifically, I am after the following information:

1. Does NHS Tayside 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 NHS Tayside 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
      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)

<table>
<thead>
<tr>
<th>Test Name</th>
<th>Test used for HoFH diagnosis at this trust Y/N</th>
<th>Test carried out by trust In-house for diagnosis of HoFH Y/N</th>
<th>Details of referral organisation/location for those tests that cannot be carried out by the trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cascade Genetic/DNA Tests</td>
<td></td>
<td></td>
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<tr>
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<tr>
<td>Other (please specify)</td>
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</tbody>
</table>

2. Does NHS Tayside 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 NHS Tayside? 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 NHS Tayside? 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 NHS Tayside? Please where possible (and applicable) provide with break down by Adult and Paediatric Patients.”

Response

Homozygous Familial Hypercholesterolaemia is a very rare condition with an incidence of 1 in 1 million in Scotland; there are currently no patients in Tayside with this diagnosis.

Due to the rarity and complexity of the condition, testing is done centrally at a genetics lab in Aberdeen.


<table>
<thead>
<tr>
<th>Document Ref.</th>
<th>FOISA Exemption Applied</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>IGTOISA6582</td>
<td>None</td>
<td>None</td>
</tr>
</tbody>
</table>

Everyone has the best care experience possible
Headquarters: Ninewells Hospital & Medical School,
Dundee, DD1 9SY (for mail) DD2 1UB (for Sat Nav)
Chair, Mrs L Birse-Stewart
Chief Executive, Grant R Archibald
Under section 20 (1) of the Act, if you are dissatisfied with the way NHS Tayside has dealt with your request, you have a right to request a review of our actions and decisions in relation to your request, and you have a right to appeal to the Scottish Information Commission.

A request for an internal review must be made in writing no later than forty working days from receipt of this response and sent to:

Head of Information Governance  
Maryfield House (South)  
30 Mains Loans  
Dundee  
DD4 7BT

Or by email to informationgovernance.tayside@nhs.net

If you are not content with the outcome of the internal review, you have the right to apply directly to the Scottish Information Commissioner for a decision. The Scottish Information Commissioner can be contacted at:

Scottish Information Commissioner  
Kinburn Castle  
Doubledykes Road  
St Andrews, Fife  
KY16 9DS

Or via the online appeal service: www.itstpublicknowledge.info/Appeal

If you have any queries about this correspondence, please contact:

Information Governance Team  
Maryfield House  
30 Mains Loan  
Dundee  
DD4 7BT

Telephone - 01382 424413  
E-mail: informationgovernance.tayside@nhs.net

Information Governance  
NHS Tayside  
09 August 2019