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Public Health
Wales

Freedom of Information request to Public Health Wales

FOI Reference:	FOI 143
Date request received	19 September 2018
Date information is due to be sent	17 October 2018

Information requested:

I am not entirely sure where this request should be directed (to health boards or Public Health Wales) so my apologies if this is not relevant to you.

I am trying to determine the scale of a rare congenital hand disease in Wales. Please will you provide information on the following. I am pursuing this information in a personal, not professional capacity. Thank you in advance for your support – I do hope this is a relatively swift exercise for NHS staff to undertake.

1. a. Annual total numbers of newly diagnosed cases of Macroductyly of the upper limb during the past 20 years; 1999-2018
b. Number of these cases where the patient is <12 years of age

2. a. Annual total numbers of operations to debulk Macroductyly of the upper limb during the past 20 years; 1999-2018
b. Number of these cases where the patient is <12 years of age

Information provided for the answer:

Thank you for your email dated 19th September 2018.

- 1. a. Annual total numbers of newly diagnosed cases of Macrodactyly of the upper limb during the past 20 years; 1999-2018**
- b. Number of these cases where the patient is <12 years of age**

Public Health Wales holds the Congenital Anomaly Register & Information Service (CARIS) for Wales.

Over the time period specified (1999 to date) CARIS has been notified of 3 cases, all below the age of 12 years.

- 2. a. Annual total numbers of operations to debulk Macrodactyly of the upper limb during the past 20 years; 1999-2018**
- b. Number of these cases where the patient is <12 years of age**

Public Health Wales is not confident that the data held on CARIS for operations as described above is complete. There is one such surgery recorded on CARIS.

We suggest that you contact Abertawe Bro Morgannwg University Health Board which has a specialist unit for plastic surgery.

Abertawe Bro Morgannwg University Health Board

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

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