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Public Health
Wales

Freedom of Information request to Public Health Wales

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| FOI Reference: | FOI 367 |
| Date request received | 17 June 2020 |
| Date information is due to be sent | N/A |

Information Requested:

The Smith-Magenis Syndrome (SMS) Foundation UK is seeking to establish a definitive demographic profile of syndrome diagnosis across the UK to develop greater support services and activities for geographical areas. More information on the foundation's mission can be found at www.smith-magenis.org.

I am writing to you under the Freedom of Information Act 2000 to request the following information from Public Health Wales:

Information regarding the population of individuals with Smith-Magenis Syndrome, this is identified by a mutation or deletion of RAI1 gene on chromosome 17p11.2:

Total population covered by the health authority

- The total number of people diagnosed with Smith-Magenis syndrome within this population
- Year of Birth
- Male / Female

Information provided for the answer:

Thank you for your recent request, Public Health Wales does not hold the data. We understand that you have already contacted the Health Boards.

We hope you are successful in finding the information you require.

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