

7 July 2020

Our Ref: RFI 34867

Dear

**Freedom of Information Act 2000
Information in Relation to Prevalence of Smith-Magenis Syndrome**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to the above which you requested on 17 June 2020 and your subsequent revised request dated 29 June 2020.

Due to the initial request exceeding the ‘appropriate limit’ I would like to submit the request again with a new limit.

Question 1. I would like to request the original questions about information held within your electronic database. This would exclude your non-electronic records.

- a) The total number of people diagnosed with Smith-Magenis syndrome within this population.***
- b) Year of Birth.***
- c) Male / Female.***

Answer 1. The Information requested is not held on an electronic/central database within the Trust. However, the Regional Genetic Service, based at Belfast City Hospital may be able to assist with accessing this information, to pursue this further you may wish to request the information from publicliaison@belfasttrust.hscni.net.

In accordance with the Freedom of Information Act 2000 this letter acts as a Refusal Notice.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital (informationgovernance@setrust.hscni.net) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner’s Office –Northern

Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

Joyce Batch
Information Governance Assistant