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Request for Information Reference: 01.23.12

FOI Direct line: 01325 743700
Email: cdda-tr.cddftfoi@nhs.net

Email only

10th January 2023

Dear

Freedom of Information Act 2000 – Request for Information

Thank you for submitting a request for information which we received on 5th January 2023 in relation to County Durham and Darlington NHS Foundation Trust (the Trust). Your request has been processed under the provisions of the Freedom of Information Act 2000 and I am now able to provide you with a response.

Your request was in relation to Bardet-biedle Syndrome and I am providing the following information in response to your specific questions:

Could i please request information relating to the below:

- **If you treat Bardet-biedle Syndrome, how many unique patients have you treated in the last 12 months?**

Zero

- **What % of these patients get a genetic diagnosis prior to them being referred onto specialist centres?**

Not applicable

- **If you do not treat Bardet-biedle Syndrome, could I request where these patients are referred to?**

Patients would be referred to tertiary genetics at Newcastle Hospitals NHS Foundation Trust.

In line with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log on the Trust's website. However please be assured that we anonymise all responses prior to adding them to the disclosure log.

I hope that this response has provided you with the information you had requested. If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me by telephone or in writing. If however, you are dissatisfied with the way in which your request has been handled and would like an internal review, you will need to contact me in writing at the above address or via cdda-tr.cddftfoi@nhs.

If you remain dissatisfied with our response following an internal review you have the right to appeal to The Information Commissioner at Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF. More information is available on their website; www.ico.gov.uk.

Yours sincerely

Corporate Records and Freedom of Information Facilitator