

Ref: FOI/GS/ID 7913

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Freedom of Information Act 2000

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to Bardet-Biedle Syndrome.

You asked: All questions are shown as received by the Trust. If you treat Bardet-biedle Syndrome, how many unique patients have you treated in the last 12 months?

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

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

Trust response:

The Trust does not currently have any patients on our caseload with Bardet-Biedle Syndrome and have not had any in the last 12 months.

This cohort of patients would normally be referred by their GP to a London Hospital. If we were referring onwards we would be referring to Guys & St Thomas NHS & Foundation Trust.