

Date: **22 August 2019**

Our reference: **FOIRQ5356**

Dear Sir/Madam,

Thank you for your request for information that you have submitted under the Freedom of Information Act 2000. Please see our response to your request below:

Your Request

- 1. In relation to the above diagnoses (PANS/PANDAS) which is currently listed in the proposed ICD-11 (shortly due for implementation), can the trust please outline its approach to diagnosing this condition and outline its proposed treatment protocols.*
- 2. If the Trust has subsequently treated children for this diagnosis or similar diagnoses (such as immune dysregulation or immune mediated behaviours) can the Trust please outline how many children it has treated.*
- 3. If the Trust has not diagnoses or treated children for this condition can the Trust please outline why it is presently not diagnosing this condition, the reason why and how it intends to comply with the implementation of the ICD-11 by 2022.*

Our Response

Great Ormond Street Hospital for Children NHS Foundation Trust (the 'Trust') is a single site, specialist tertiary paediatric trust. Your request does not appear to be seeking to obtain recorded information under the terms of the Freedom of Information Act (FOIA) 2000; but rather a request to obtain advice and/or an explanation on its approach and intention to complying with the implementation of ICD-11 by 2022.

The FOIA was created for the purpose of making a request for recorded information only. As you have requested an outline of the above information, it is seeking advice, an opinion, or an explanation, which does not fall under the terms of the FOIA. We have therefore contacted the relevant department for assistance in answering your request, in which, they have responded below:

"Patients are reviewed in line with the way they present; or are referred to GOSH, for example: if they present primarily with a movement disorder, psychiatric disorder; developmental disorder; or any identified

infections, such as immunodeficiency or immune dysregulation, they will be reviewed and treated as appropriately. This process takes place in consideration of ICD, Multidisciplinary input, including input from local services that are enlisted as and when appropriate.”

We hope the above information has helped to answer your questions.

Yours sincerely

Freedom of Information team

Great Ormond Street Hospital for Children NHS Foundation Trust

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