



**The Clatterbridge
Cancer Centre**
NHS Foundation Trust

Clatterbridge Road
Bebington
Wirral
CH63 4JY

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Date: 18th July 2022

Re: Freedom of Information Request
Ref: 250-2022

Thank you for your email dated the 16th July, requesting information in relation to PANDAS.

The information that you require is as follows:

i) PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections) ii) PANS (Paediatric Acute-onset Neuropsychiatric Syndrome) iii) Long COVID iv) immune mediated neuro behaviour conditions v) neuro psychiatric conditions vi) behavioural changes or altered behaviour vii) sudden onset tics viii) sudden onset ocd ix) sudden onset eating difficulties x) bodily distress disorder xi) autoimmune encephalitis with an idiopathic cause xii) idiopathic transverse myelitis xiii) immune dysregulation xiv) psychiatric disorder

1) Please can you provide any a) clinical guidance, b) policy, c) procedure d) diagnostic pathway e) treatment pathways f) management pathway g) the clinical classification ICD-11 code or the code which would have traditionally been used if there is an absence of code for each of the conditions i)-xiv) above in paediatric patients.

2a) Please could you also provide for each condition or probable/ suspected condition i)-xiv) above the number of paediatric patients presenting with these conditions for each year for the past 5 years? & b) how many were referred for treatment c) how many referrals rejected d) how many referrals were accepted e) how many patients were referred to another service outside of the trust. Please could this be provided in a table format?

3) Please could you provide me with any minutes of meetings which decided how patients are treated following the British Paediatric Neurology Association Consensus Statement dated April 2021 and details of any changes in how the trust treated or diagnosed patients following this statement along with details of who made the decision to implement any changes.

I can confirm that our Trust does not hold any information in this regard. Our Trust is a tertiary specialist cancer treatment centre. Therefore, the information you have requested is not applicable to our Trust in this instance.

Should you require any further information please do not hesitate to contact me on the email address provided below.

Please remember to quote the reference number above in any future communications.

If you are dissatisfied with the handling of your request, you have the right to ask for this to be investigated internally.

If you are dissatisfied with the information you have received, you have the right to ask for an internal review.

Both processes will be handled in accordance with our Trust's Freedom of Information Policy and the Freedom of Information Act 2000.

Internal investigation and internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to: Freedom of Information Review, The Clatterbridge Cancer Centre NHS Foundation Trust, Clatterbridge Road, Bebington, Wirral, CH63 4JY

If you are not satisfied with the outcome of the internal investigation/review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

In order for us to ensure customer satisfaction and to monitor compliance with the Freedom of Information Act 2000, we would be grateful if you could take a couple of minutes to complete a short feedback form via the link below:

<https://forms.office.com/r/eLzHXi49Ea>



Kind Regards,

Margaret Moore
Information Governance Assistant
Email: ccf-tr.foi@nhs.net