FOI 2655

Date 22/11/2023

Dear Requester,

Thank you for your Freedom of Information request. Please note, this is a cross-site response for Bedford site and Luton site.

You asked:

In 2022 I sent you a FOI request asking how you treated conditions or probable or suspected conditions listed as i-iii) below?

 i) Pandas (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections) ii) PANS (Paediatric Acute-onset Neuropsychiatric Syndrome) iii) immune mediated neuro behaviour conditions.

Following this request there has been a press release in February 2023, a copy is attached, it can also be found via the BPNA website ([https://bpna.org.uk/?page=pans-pandas](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fbpna.org.uk%2F%3Fpage%3Dpans-pandas&data=05%7C01%7Cbhn-tr.foibedfordshirehospitals%40nhs.net%7C664f2789f77b4cf7adfd08dbd26247c0%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638335091936218166%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=mW%2FYeNpT%2B%2FFEN11XhdbWIZ33lcb7x0od%2BCmo%2FaEjPeU%3D&reserved=0).)

Following this update from the working group. Please could you provide me with the following:

1. Tell me whether the Trust/ Hospitals treatment and diagnostic criteria has changed as a result of the working group statement. If it has, please can you send me the copies of the new policy / procedure for treatment and diagnostic pathway?

No. We have been having same approach as investigation for neuroinflamatory conditions. Still there is controversy as to clear identification criteria for PANS and PANDAS. We identify as possible neuroinflammatory conditions and manage by referring to CAMHS for support.

1. **Please could you also provide for each condition or probable/ suspected condition i)-iii) above the number of paediatric patients presenting with these conditions for each** **year for the past 1 year and** **iv)** **how many patients were referred to another service outside of the trust?**

We get 1-2 neuro inflammatory conditions presenting with neuropsychiatric symptoms per year. We do not keep a data base for this. This is an estimate. We refer to Addenbrookes hospital for most of these conditions.

1. Please could you provide me with any minutes of meetings which decided how patients are treated following the British Paediatric Neurology Association update on the working group in February 2023 and who made the decision to implement any changes.

We do not have an MDT structure for managing these conditions. There are no minutes of discussions available

1. Whether the Trust/ Hospital has sought commissioning to treat this cohort of patients, who did it approach e.g. ICB or NHSE and whether this was approved or rejected along with the reasons why or timescales for implementation if relevant.

We do not have a cohort of patients hence did not seek for help.

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If you are not satisfied with the Trust review under the Freedom of Information Act 2000 you may apply directly to the Information Commissioners Officer (ICO) for a review of your appeal decision. The ICO can be contacted at: ICO, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF www.ico.org.uk

Yours sincerely,

*FOI Officer*

Bedfordshire Hospitals NHS Foundation Trust