BPNA
British Paediatric Neurology Association

17 March 2026

HM Senior Coroner
Tanyka Rawden
Office of H.M Coroner
Watery Street
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[redacted] – RE: Death of Mia Maisie Lucas

FAO: HMSC Tanyka Rawden

Many thanks for contacting me regarding the tragic death of Mia Maisie Lucas and enclosing your Report to Prevent Future Deaths.

In the Matters of Concern you state:

‘The Court heard there is no national guidance for clinicians on when to consider, and how to diagnose Autoimmune Encephalitis. Without this I am of the view there is a risk the condition will not be identified which gives rise to a risk that deaths will occur in the future.’

I can confirm that there are no specific current guidelines on Autoimmune encephalitis in Children and Young People in the UK. In 2012 a guideline – ‘Management of suspected viral encephalitis in children - Association of British Neurologists and British Paediatric Allergy Immunology and Infection Group National Guidelines’ was published in Journal of Infection, and whilst this guideline does reference Autoimmune Encephalitis it is mainly focussed around infective encephalitis with more limited information on Autoimmune Encephalitis. There is a greater understanding since then of the range of presentations, including with psychiatric symptoms. I understand that this guideline is currently being updated – but has not been published yet.

There are many publications in the medical literature describing the wide range of presentations and treatments of Autoimmune Encephalitis.

However, it would be very valuable to have a NICE (National Institute for Health and Care Excellence) Guideline on Autoimmune Encephalitis to provide best-practice advice in diagnosing and managing Auto-immune encephalitis in the UK and standardising care across the UK for children and young people presenting with Autoimmune Encephalitis. I note that you copied your report to Wes Streeting (as I have in my reply) who would be in a position to support the commissioning of a NICE Guideline and the British Paediatric Neurology Association would be keen to involved in this.

One other issue that is worth commenting on is that there is inequality across the UK in testing for NMDA receptor antibodies. We asked Paediatric Neurology centres in the UK how long they were waiting for their antibody results and more than half of centres are waiting for more than 3 weeks with over a third waiting for at least 6 weeks. This delay in diagnosis means delayed treatment which is associated with significantly poorer outcomes. It would be important to work to a more rapid turnaround of NMDA receptor antibody tests across the UK in order to improve outcomes from this condition which would mean utilising laboratories who can provide results in less than one week. There are a number of bureaucratic hurdles to cross to facilitate this – again something that could be supported through Department of Health.

Please let me know if the British Paediatric Neurology Association can be of further help in learning from Mia’s death.

Yours sincerely,

[redacted]

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