



Department  
of Health &  
Social Care

From Jo Churchill MP  
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14 May 2021

Dear Ms Hayes

Thank you for your letter of 1 March 2021 to Matt Hancock about the death of Luke Owen Jackson. I am replying as Minister with responsibility for child health and I am grateful for the additional time in which to do so.

Let me start by saying how deeply sorry I am for the failings in care highlighted in your report. That your investigation found that Luke's cardiac arrest was avoidable had he received the right treatment for Hypokalaemia is extremely distressing and I offer my most heartfelt sympathies to Luke's parents and all those affected by his death. Clearly, we must take the learnings from Luke's death to ensure patients continue to receive the very best care from the NHS.

In preparing this response, my officials have made enquiries with NHS England and NHS Improvement (NHSEI); the National Institute for Health and Care Excellence (NICE); and the Royal College of Paediatrics and Child Health (RCPCH).

I am informed that in its response to your report, the Medway NHS Foundation Trust has explained the action it has taken to update its paediatric guidelines in relation to patients with myopathies. This is to include the factors that doctors need to be aware of in clinical presentation; the requirement for patients to be fully assessed prior to discharge by at least a Registrar level clinician; and, to make clear the low threshold for admission to high dependency and the level of monitoring and potassium replacement that should be undertaken.

I am pleased to note the actions taken by the Trust. It is vitally important that the Trust takes all possible learnings from Luke's death, and that learnings are also taken forward nationally.

In relation to guidance that is available to clinicians, I am advised by NICE that it has issued guidance on *intravenous fluid therapy in children and young people in hospital*

(NG29<sup>1</sup>), updated in June 2020. While the guideline does not give recommendations relating to specific conditions, it provides advice on assessment (including checking electrolytes) before starting intravenous (IV) fluids (see recommendation 1.2.3)); and, recommends that plasma electrolyte concentrations are measured using laboratory tests when starting IV fluids (and then at least every 24 hours, or more frequently as indicated (see recommendation 1.2.4)).

The recommendations in this guideline represent the view of NICE, arrived at following careful consideration of the evidence available. When exercising their judgement, clinicians are expected to take this guideline fully into account, alongside the individual needs of their patient. However, it is not mandatory to apply the recommendations, and the guideline does not override the responsibility of clinicians to make decisions appropriate to the specific circumstances of the individual.

I am advised that the choice of fluid, the frequency with which electrolyte concentrations are measured after starting IV fluids, and the subsequent escalation of care, depend on the clinical picture and ongoing assessment.

It is the view of NICE that the current general guidance about assessment, monitoring, and altering care as indicated is appropriate.

Raising awareness among clinicians of how to recognise and manage hypokalaemia in children with myopathies is essential. I am aware that the RCPCH has shared your report with the British Paediatric Neurology Association (the BPNA) and that in its response to you, the RCPCH has explained the existing courses run by the RCPCH and the BPNA, aimed at health professionals, on the recognition and management of neuromuscular disorders.

I am also pleased to note that the RCPCH will consider further work to raise awareness of the issues raised by Luke's death and to promote the current NICE guidance on replacement fluid therapy in children and young people.

I hope this response is helpful. Thank you for bringing these important matters to my attention and once again I offer my sincere condolences to Luke's family.



**JO CHURCHILL**

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<sup>1</sup> [Overview | Intravenous fluid therapy in children and young people in hospital | Guidance | NICE](#)