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Catherine Wood Assistant Coroner Suffolk

Dear Ms Wood

Re: RCPCH Response to the Inquest Touching the Death of Nuel-Junior Kerlii Dzernjo A Regulation 28 Report – Action to Prevent Future Deaths

Thank you for sharing your report with us regarding the tragic and untimely passing of Nuel-Junior. We were saddened to read the circumstances surrounding Nuel-Junior's death and have discussed with senior colleagues within the RCPCH and the British Paediatric Allergy, Immunity and Infection Group (BPAIIG). Thank you for confirming in a separate correspondence that the doctors knew that Nuel-Junior was immunocompromised, and that he was initially not particularly "unwell" and presented with typical signs of chickenpox (including a temperature and spots/lesions). You described further that Dr Louis Grandjean, an independent paediatric expert instructed by the court, was of the view that the guidance was unclear.

Whilst we cannot comment on the specific details around Nuel-Junior's passing, we have read your report carefully and would like to offer a response to your concerns, and other areas where the Royal College of Paediatrics and Child Health will bear most impact.

Clarity on guidance

BNFC (British National Formulary for Children) guidance is clear insofar as there is only one recommendation for varicella infection in the immunocompromised to be administered intravenously. I have provided a snippet from the BNFC guidance¹ here for ease:

Varicella zoster (chickenpox), treatment in immunocompromised

By intravenous infusion

Child 3 months-11 years

500 mg/m² every 8 hours usually for 5 days.

Child 12-17 years

10 mg/kg every 8 hours usually for 5 days.

¹ https://bnfc.nice.org.uk/drugs/aciclovir/

It is possible that guidance from other sources may have added confusion for the treating healthcare team as we are aware that there can be a variety of information sources that clinicians draw on to determine treatment options locally. However, BNFC guidance is clear.

The College will be interested to understand from NICE, whom you are also seeking views, on their plans to review their guidance and whether an update is needed to clarify guidance for immunocompromised children.

Access to specialist paediatric infectious disease advice for complex cases

I have shared your report with the BPAIIG for further advice on actions the College could take to prevent future deaths of this kind. They have identified the importance, for hospitals providing care to children, of having regular input from an infectious disease paediatric subspecialty who are readily available to help improve clinical decision making and patient pathways.

Communication with families

The College will learn from your report, especially with respect of working with our members on the importance of continually improving how we engage with families in care settings. This includes how paediatricians can better facilitate parents and families to share their understanding of how ill their child is. The College has worked with NHS England and the Royal College of Nursing to develop a paediatric early warning system (PEWS) to spot deterioration.² The new national inpatient PEWS includes a parental concern trigger where parental or carer concern will lead to escalation of the child's care, regardless of other assessments.

The College is also engaging with NHS England and the Patient Safety Commissioner on how Martha's Rule – a new process that stipulates the right to request a second clinical review - will be implemented nationally. This recognises the importance of a structured system that obtains information relating to a patient's condition directly from patients and their families at least on a daily basis.³

Sharing information for quality improvements

The College will be sharing information and suggestions for local improvement from your report with our paediatric members via its <u>patient safety portal</u>, including the promotion of the BNFC guidance to improve awareness across the profession. The information within your report will also be shared for discussion with the RCPCH Clinical Quality in Practice group in early Spring, where further actions may be identified.

The RCPCH supports the recommendation from the Joint Committee on Vaccination and Immunisation on a universal varicella vaccination programme to be introduced as part of the routine childhood schedule.⁴ We continue to advocate for rapid implementation of the NHS Vaccination Strategy to bring forward opportunities to protect communities and save lives.

² https://www.rcpch.ac.uk/resources/paediatric-early-warning-system-england

³ <u>https://www.rcpch.ac.uk/news-events/news/rcpch-responds-patient-safety-commissioners-recommendations-marthas-rule</u>

⁴ https://www.gov.uk/government/publications/childhood-varicella-vaccination-programme-jcvi-advice-14-november-2023/jcvi-statement-on-a-childhood-varicella-chickenpox-vaccination-programme

Thank you for seeking our views and reminding us of the importance of this work. Our sincere condolences are with Nuel-Junior's family.

Yours sincerely



RCPCH President