

Regulation 28: REPORT TO PREVENT FUTURE DEATHS

NOTE: This form is to be used **after** an inquest.

REGULATION 28 REPORT TO PREVENT DEATHS THIS REPORT IS BEING SENT TO:

1 The Food Standards Agency

1 CORONER

I am Tom OSBORNE, Senior Coroner for the coroner area of Milton Keynes

2 CORONER'S LEGAL POWERS

I make this report under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and regulations 28 and 29 of the Coroners (Investigations) Regulations 2013.

3 INVESTIGATION and INQUEST

On 02 November 2022 I commenced an investigation into the death of Rohan GODHANIA aged 16. The investigation concluded at the end of the inquest on 21 July 2023. The narrative conclusion of the inquest was:

The deceased was admitted to West Middlesex Hospital on 16th August 2020. His hyperammonaemia and OTC deficiency was not diagnosed. The failure to carry out a test for ammonia that would have revealed the hyperammonaemia resulted in a lost opportunity to render further medical treatment that may, on the balance of probabilities, have prevented his death. He died on 18th August 2020.

4 CIRCUMSTANCES OF THE DEATH

The deceased consumed a high protein drink on 15th August 2020 and became unwell. He was admitted to West Middlesex Hospital. Advice was taken from the neurologists at Charing Cross Hospital who advised that he should be tested for ammonia. The test was not carried carried out. His condition deteriorated and he died from Ornithine Transcarbamylase Deficiency (OTC) on the 18th August 2020.

5 CORONER'S CONCERNS

During the course of the investigation my inquiries revealed matters giving rise to concern. In my opinion there is a risk that future deaths could occur unless action is taken. In the circumstances it is my statutory duty to report to you.

The MATTERS OF CONCERN are as follows:

(brief summary of matters of concern)

High protein supplements and drinks are easily accessible to the general public, yet their labels fail to adequately inform consumers about the potential dangers posed to individuals with urea cycle disorders, such as Ornithine Transcarbamylase (OTC) deficiency. This genetic disorder can lead to severe medical emergencies, requiring immediate medical intervention to prevent life-threatening complications. This disorder can be triggered by the sudden increased ingestion of protein.

Consideration should be given as to whether the labels should prominently display a warning about the potential risks for individuals with an undiagnosed urea cycle disorder and include clear and concise information on symptoms of this and the importance of seeking immediate medical advice.



6 ACTION SHOULD BE TAKEN

In my opinion action should be taken to prevent future deaths and I believe you (and/or your organisation) have the power to take such action.

7 YOUR RESPONSE

You are under a duty to respond to this report within 56 days of the date of this report, namely by October 02, 2023. I, the coroner, may extend the period.

Your response must contain details of action taken or proposed to be taken, setting out the timetable for action. Otherwise you must explain why no action is proposed.

8 COPIES and PUBLICATION

I have sent a copy of my report to the Chief Coroner and to the following Interested Persons

The family of Rohan Godhania West Middlesex Hospital NHS FT Imperial College NHS FT

I am also under a duty to send a copy of your response to the Chief Coroner and all interested persons who in my opinion should receive it.

I may also send a copy of your response to any person who I believe may find it useful or of interest.

The Chief Coroner may publish either or both in a complete or redacted or summary form. He may send a copy of this report to any person who he believes may find it useful or of interest.

You may make representations to me, the coroner, at the time of your response about the release or the publication of your response by the Chief Coroner.

9 Dated: 09/08/2023

Tom OSBORNE

Senior Coroner for Milton Keynes