# Regulation 28: Prevention of Future Deaths report

**Sophie RYAN-PALMER (died 17.07.13)**
**Katie JOYCE (died 06.10.13)**
**Ryan Stephen LOUGHRAN (died 10.07.13)**
**Muhanna Talal Hamad ALHAYANY (died 28.08.13)**

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| | **THIS REPORT IS BEING SENT TO:**<br><br>**1. NHS England**<br>**PO Box 16738**<br>**Redditch**<br>**B97 9PT** |
| 1 | **CORONER**<br><br>I am: Coroner ME Hassell<br>Senior Coroner<br>Inner North London<br>St Pancras Coroner's Court<br>Camley Street<br>London N1C 4PP |
| 2 | **CORONER'S LEGAL POWERS**<br><br>I make this report under the Coroners and Justice Act 2009, paragraph 7, Schedule 5, and<br>The Coroners (Investigations) Regulations 2013, regulations 28 and 29. |
| 3 | **INVESTIGATION and INQUEST**<br><br>On various dates in 2014, I commenced investigations into the deaths of Sophie Ryan-Palmer, Katie Joyce, Ryan Loughran and Muhanna Alhayany, four children who had died in 2013 following treatment at the National Hospital for Sick Children at Great Ormond Street in London. The investigation concluded at the end of the inquest earlier today. I made a narrative determination, which I attach. |
| 4 | **CIRCUMSTANCES OF THE DEATH**<br><br>As you will see from the narrative, all the children were treated with stem cell transplants, but it later appeared that there might be an issue with the cryopreservation of the stem cells. |

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| | Identifying the fact that there was any problem at all, still less the nature of that problem, was not straight forward. Those treating the children and then investigating potential causes of their failure to recover, were significantly hampered by the fact that they had no means of benchmarking autologous stem cell engraftment.<br><br>This put these children at a significant disadvantage and is likely to do the same for some other children with cancer, not just at GOSH but all over the country. |
| 5 | **CORONER'S CONCERNS**<br><br>During the course of the inquest, the evidence revealed matters giving rise to concern. In my opinion, there is a risk that future deaths will occur unless action is taken. In the circumstances, it is my statutory duty to report to you.<br><br>The **MATTERS OF CONCERN** are as follows.<br><br>1. I heard at inquest that there is concern within the medical community over the whole governance structure for autologous stem cell transplant in this country, most especially regarding the lack of any one appropriate control risk group with a national lead.<br><br>2. I also heard that there is at present no disease specific national benchmarking available for autologous stem cell engraftment. The relevant results of an international SIOPEN trial (that aspect of which closed in 2011) have not been made publicly available.<br><br>Those treating children following autologous bone marrow transplant, do not know how many days to recovery is normal, so they do not know what is abnormal, and whether the results in their own hospital fall below the results elsewhere.<br><br>The failure to unlock the results of the SIOPEN trial could, therefore, compromise the optimal care of some children with cancer. |
| 6 | **ACTION SHOULD BE TAKEN**<br><br>In my opinion, action should be taken to prevent future deaths and I believe that you have the power to take such action. |

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| 7 | **YOUR RESPONSE**<br><br>You are under a duty to respond to this report within 56 days of the date of this report, namely by 26 January 2015. I, the coroner, may extend the period.<br><br>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**<br><br>I have sent a copy of my report to the following.<br><br>• HHJ Peter Thornton QC, the Chief Coroner of England & Wales<br>• Care Quality Commission for England<br>• Professor Dame Sally Davies, Chief Medical Officer for England<br>• [redacted] and [redacted], parents of Sophie<br>• [redacted] and [redacted], parents of Katie<br>• [redacted] and [redacted] parents of Ryan<br>• [redacted] and [redacted], parents of Muhanna<br>• [redacted], Divisional Director, GOSH<br>• [redacted] Director, Planer plc<br>• [redacted], President, SIOPEN<br><br>I am also under a duty to send the Chief Coroner a copy of your response.<br><br>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 Senior Coroner, at the time of your response, about the release or the publication of your response by the Chief Coroner. |
| 9 | **DATE** **SIGNED BY SENIOR CORONER**<br><br>25.11.14 |