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David Rees AM Chair, Health and Social Care Committee

18th June 2015

Dear David,

Thank you for your letter of the 27 May, regarding Petition P-04-603 Helping babies born at 22 weeks to survive.

I am writing to inform you of activity already underway, which will hopefully address the two issues raised in your letter.

Ms Emma Jones, the petitioner, took up the offer of a meeting with Heather Payne, senior medical officer for maternal and child health, and Edward Rees, head of obesity prevention and children's health, on the 18 February. The meeting was very positive and officials have already taken forward Ms Jones' helpful suggestions about what parents want from clinicians when they experience such a sad situation.

Following the discussion with Ms Jones, it was agreed that the Welsh Government should raise the issue of clinical management of very premature infants with Maternity and Paediatric colleagues to ensure a consistent Wales wide approach and appropriate management. In response to this, the All Wales Neonatal Network Management Group and the All Wales Maternity Network have agreed to work together to explore existing clinical guidelines and ensure a consistent All Wales approach. This piece of work is currently being conducted and they will report back in July with a Clinical Consensus Document for use across NHS Wales.

For information, the clinical guidance on resuscitation and ongoing life support for very premature babies is not Welsh Government guidance but comes from the professional organisation (British Association of Perinatal Medicine, BAPM), which has the most experience in caring for sick and premature babies. Their guidance is based on sound research evidence of outcomes of intervention in the very tiniest and sickest of babies who sadly, so often cannot be helped even by the most advanced medical care.

In addition to consideration of the clinical management and guidance, officials meeting with Ms Jones highlighted the need for parents in this situation to be well informed and be active participants and decision makers in the care given to them and their child. Therefore, as part of their work, the Maternity Group and Neonatal Network have been asked to describe the care pathway for mothers and babies in such a situation, which would include provision of palliative and bereavement care.



To ensure that parents' views are considered, and that the communication of the care pathway is appropriate for them, Ms Jones has kindly agreed to share her views with the Group producing the Clinical Consensus Document and care pathway.

In response to your questions, I would expect all hospitals in Wales to offer care in line with the Clinical Consensus Document, once issued, with appropriate communication with parents being a core part of the care pathway. Such a document could be subjected to clinical audit at appropriate intervals.

Best wishes

DR RUTH HUSSEY OBE

CHIEF MEDICAL OFFICER / MEDICAL DIRECTOR NHS WALES