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10 February 2015

Dear Mr Woolley

**Sudden deaths of Robert James STUART & Darren Llewellyn HUGHES  
Regulation 28 Report to Prevent Future Deaths**

We thank you for the areas highlighted within the Report to Prevent Future Deaths dated 18th December 2014 following the inquest which concluded on 4<sup>th</sup> December 2014.

We note that during the course of the inquest evidence revealed matters which gave rise for concern and that, in your opinion, there is a risk that future deaths will occur unless action is taken. NHSBT has already completed a number of actions to address these areas of concern.

Following notification of the sad deaths of both Mr. Hughes and Mr. Stuart in December 2013 NHSBT reviewed the incident thoroughly and we have done so again in light of both the comments made during the inquest and the subsequent verdict.

**Matters of Concern**

NHSBT notes your concern that the core donor data form (CDDF) could have contained more information as to the second lumbar test performed on the donor and could have given the results of the first lumbar puncture test. Further, it is noted that you are concerned that there was information available on the medical microbiology report which was not passed on to the accepting transplant centre.

You are of the view that had this information been available to [REDACTED], the transplanting surgeon, then it may have caused more questions to be asked and aided in the acceptance process.

Your concerns are also noted that NHSBT should employ systems to ensure the capture and transmission of all relevant information to the accepting transplant centre and that specialist nurses should be in a position, if required, to certify that all relevant and available information has been transmitted.

**NHSBT's position**

- 1) Systems to capture and provide information to transplant centres

The NHSBT Board, at its January meeting, approved expenditure to change the way in which Specialist Nurses record and transmit data electronically to transplant centres. This will simplify the work of the nurses, reduce the risk of errors in recording the data in NHSBT systems and increase the amount of data transmitted to transplant centres via EOS. This is a major IT development and we

expect it to be fully operational by April 2016. In the interim period, we continue to remind the nurses of the importance of capturing and providing key information accurately and fully.

## 2) Specialist nurse certification of information

NHSBT shares your concern regarding the ability of capturing all relevant information during donor characterisation however there are many reasons why our specialist nurses in organ donation are not in a position to guarantee the information provided via the CDDF.

Throughout the NHS, multiple processes and system are in place which are used to request and report data. Those reports are also issued at uncertain times. Due to the different systems, time scales and methods used in providing and obtaining information, it is not possible to provide this complete reassurance. Often reliant upon the clinical information provided to them by treating clinicians, our specialist nurses are not in a position to certify that all relevant and material information has been made available.

This problem could be overcome by the introduction of a single UK-wide unified clinical records system. However, until such time, the specialist nurses are always available by telephone to provide clarification to the recipient teams and to seek and provide further information from treating clinicians if required.

## 2) Microbiology results

Your observations regarding the microbiology report are noted however NHSBT has obtained written confirmation from the independent testing reference laboratory that although the first blood sample taken at the donor hospital on 25<sup>th</sup> November 2013 was received for testing the same day, the enterovirus, parechovirus, HSV and VZV results were not available until 3<sup>rd</sup> January 2014. Additional tests of meningococcal and pneumococcal were requested as additional tests on the 2<sup>nd</sup> January 2014.

Further, whilst a second blood sample was taken at the donor hospital on 28<sup>th</sup> November 2013, received by the testing reference laboratory the following afternoon, the enterovirus, parechovirus, HSV and VZV results were not made available until 3<sup>rd</sup> December 2014.

Similarly, the enterovirus, parechovirus, HSV and VZV results of the CSF sample taken at the donor hospital on 27<sup>th</sup> November 2013 were not made available until 3<sup>rd</sup> December 2013. Additional tests of meningococcal and pneumococcal were requested on 10<sup>th</sup> January 2014 and were made available on 13<sup>th</sup> January 2014.

As such, those results could not have impacted upon the decision to transplant on 30<sup>th</sup> November 2013.

### Shared learning

This sad case has been shared widely with our specialist nurses in organ donation, as well as transplant surgeons and intensive care staff via the NHSBT governance structure. This has included a brief outline within a previous edition of 'Cautionary Tales', which is a method of sharing key cases with the wider transplant community. The decision was made to not include a full summary prior to the inquest as NHSBT did not wish to impact upon proceedings, but a full case review, together with learning points will now be included in the March 2015 edition.

Learning from this case has also been shared with the specialist nurses via both a case study presentation and NHSBT memo to highlight the importance of including all available relevant

information on the core donor data form. Further, the overview report of [REDACTED] and [REDACTED], copies of which were disclosed prior to the inquest to all interested parties, has also been shared with our specialist nurses to ensure that the key learning points from this incident are known.

In March 2015 NHSBT will host a working group where we will bring together clinicians, pathologists and other clinical colleagues to discuss what we can do to reduce the risk of a similar recurrence. The recommendations from that meeting will be widely circulated.

As a direct result of this incident, NHSBT has commenced an audit in order to review the primary records for organ donors and to assess the accuracy and completeness of the transfer of information from medical case notes to the donor file / EOS. This audit tests the first stage of the donation process and will report on a monthly basis with quarterly and annual reviews. This audit is being undertaken with the cooperation of a number of NHS Trusts.

These deaths, and that of the donor, were the 5<sup>th</sup>, 6<sup>th</sup> and 7<sup>th</sup> recorded cases in the world which have been caused by the halicephalobus nematode and I note that you ask for an article to be written in collaboration between the pathologist, the transplant centre and the microbiologists concerned in the inquest. Whilst I appreciate that this recommendation is for the attention of University Hospital of Wales, this work is already underway. During the course of the inquest NHSBT's Professor [REDACTED], NHSBT's Associate Medical Director for Organ Donation and Transplantation discussed this point [REDACTED] UHW Medical Director who has kindly agreed to lead on the written account. I enclose a copy of [REDACTED] formal request of 21<sup>st</sup> November 2014 for the sake of completeness.

Also enclosed are NHSBT's action plans to illustrate the action already taken by the organisation in response to this incident and the subsequent independent reports.

I hope you are assured that NHSBT has undertaken appropriate action to prevent future deaths.

Yours sincerely

[REDACTED]

Ian Trenholm  
Chief Executive