REPORT TO PREVENT FUTURE DEATHS

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** **1. The Chief Executive, NHSBT Head Office** **2. The Chief Executive, University Hospital of Wales, Cardiff**
1	**CORONER** I am Christopher John Woolley, Assistant Coroner, for the Coroner area of Cardiff and the Vale of Glamorgan
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 27th December 2013 I commenced an investigation into the deaths of Robert James Stuart and Darren Llewellyn Hughes. The investigation concluded at the end of the inquest on 4th December 2014. The medical cause of death for each was: 1.A Meningoencephalitis 1B Halicephalobus nematode meningoencephalitis following renal transplant 1C Halicephalobus nematode infected transplanted Kidney Pneumococcus meningitis. I returned a narrative conclusion as follows: **Robert James Stuart** Robert James Stuart died from Meningoencephalitis on the 17th December 2013, after undergoing a kidney transplant on the 30th November 2013. The source of the infection was the transplanted kidney and the agent of infection was the Halicephalobus nematode present in this kidney. The kidney had been rejected by several transplant centres before it was accepted for Mr Stuart, either because of its poor function or because of the donor's cause of death. It was not rejected because of the Halicephalobus nematode, or accepted in spite of it, as this organism is almost unknown to medical science and there was no test for it in the circumstances of this transplant. Robert James Stuart died from the unintended consequences of necessary medical intervention. **Darren Llewellyn Hughes** Darren Hughes died from Meningoencephalitis on the 19th December 2013, after undergoing a kidney transplant on the 30th November 2013. The source of the infection was the transplanted kidney and the agent of infection was the Halicephalobus nematode present in this kidney. The kidney had been rejected by several transplant centres before it was accepted for Mr Hughes, either because of its poor function or because of the donor's cause of death. It was not rejected because of the Halicephalobus nematode, or accepted in spite of it, as this organism is almost unknown to medical science and there was no test for it in the circumstances of this transplant. Darren Hughes died from the unintended consequences of necessary medical intervention.
4	**CIRCUMSTANCES OF THE DEATH**

	Both Mr Stuart and Mr Hughes underwent a kidney transplant on the 30th November 2013. The kidney was accepted from a donor who had died of meningitis of unknown cause. The kidneys were placed on the fast track scheme and were both accepted by Cardiff UHW after being rejected by other centres either because of cause of death or poor function. Unbeknown to anyone involved in the transplant process the kidneys were infected by the Halicephalobus nematode. This is recorded as having caused deaths in horses but had been noted as the known cause of death in only four human beings previously, all in the USA. The transplant operations were successful and there were no undue concerns after the operations, although Darren Hughes was quite poorly this had been anticipated. Darren Hughes remained in hospital but Robert Stuart was discharged after making excellent progress. On 10th December Robert Stuart became very confused and was re-admitted to hospital. The condition of Darren Hughes also began to deteriorate. Both were admitted to critical care. The hospital sought help from national experts to establish what was wrong with both patients with the working diagnosis being a viral infection. Robert Stuart died on the 17th December 2013 and Darren Hughes on the 19th December 2013. It was only at post-mortem that the agent of the meningoencephalitis was discovered, namely the Halicephalobus nematode.
5	**CORONER'S CONCERNS** 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. The **MATTERS OF CONCERN** are as follows. – **For the Chief Executive, NHSBT** (1) The core donor data form 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. (2) There was information available on the medical microbiology report which was not passed on to the accepting transplant centre. Had this information been available to the accepting consultant [redacted] then it may have caused more questions to be asked and aided in the acceptance process. The Coroner is concerned that NHSBT should employ systems to ensure the capture and transmission of all relevant information to the accepting transplant centre, and that SN-ODs should be in a position if required to certify that all relevant and available information has been transmitted. **For the Chief Executive, UHW Cardiff** (1) The Kidneys were accepted by the transplant centre following a telephone conversation between the consultant and the transplant coordinator. The Coroner heard that all consultants have access to the EOS system but that the consultant did not use it on this occasion. The Coroner is concerned that a viewing of the EOS system should be standard practice by all accepting consultants/centres before a decision is made, as the information on EOS is much fuller than anything that can be conveyed over the telephone. (2) The kidneys were accepted by the consultant acting alone. The Coroner heard evidence that in many centres the acceptance process is conducted on a "team" basis, with the consultant accepting advice from microbiologists and even other on call consultant surgeons. The Coroner is concerned that a team approach offers the most informed method of decision making, not only over the decision to accept organs but also over the nature and duration of prophylactic anti-viral therapy. The Coroner is concerned to hear about any action that is being taken over this in the transplant centre. (3) The Coroner heard that a standard consent form is used for all operations, and heard evidence that this has proved unsatisfactory for transplant operations where issues have to be covered that are not catered for by the standard form

	(4) These deaths represent (including the donor) the 5th, 6th and 7th recorded cases in the world of deaths caused by the Halicephalobus nematode. They are the first ever recorded deaths caused by human to human transmission. The Coroner is concerned that a written account of these deaths should be made available to the wider transplant community and that an article should be written for an appropriate journal (subject to consents from the families of the deceased). Such an article could be written in collaboration between the pathologist, the transplant centre and the microbiologists concerned in this inquest.
	ACTION SHOULD BE TAKEN In my opinion action should be taken to prevent future deaths and I believe that (1) The Chief Executive, NHSBT and the Chief Executive, UHW Health Board Cardiff 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 February 12th 2015. 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 1. [redacted] 2 [redacted] I have also sent it to the following persons: 1. Chief Medical Examiner for University Hospital of Wales 2. Dr [redacted], Regulation Manager, Human Tissue Authority I am also under a duty to send the Chief Coroner a copy of your response. 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	**18th December 2014** **C J Woolley** **Assistant Coroner, Cardiff and the Vale of Glamorgan**