Witness Name: Dr Muriel Louise Tillyer
Statement No.: WITN3298003
Exhibits: WITN3298004
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DR MURIEL LOUISE TILLYER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 26 May 2020

I, Dr Tillyer, will say as follows: -

Section 1: Introduction

Dr Muriel Louise Tillyer

GRO-C

Date of birth GRO-C 1950
MB.ChB, FRCP, FRC.Path

Consultant Haematologist Posts

1. Senior Lecturer in Haematology, London Hospital Medical College, and Honorary Consultant Haematologist, Newham General Hospital and Royal London Hospital, 1983-1997. I provided a comprehensive clinical haematology service at Newham General Hospital, and a specialist haemoglobinopathy service at Royal London Hospital, and later at Barts & The London Hospitals. I ran a joint haematology/obstetric clinic at Royal London Hospital for women with haematological problems in pregnancy. I did not have responsibility for haemophilia care in this post.

2. Consultant Haematologist, GRO-B, 1997-2006. I provided a comprehensive clinical haematology service at GRO-B, and was also Haemophilia Director for its medium sized Haemophilia Centre. I was lead clinician for haemoglobinopathies and haemostasis, and ran a service for women with haematological disorders in pregnancy. I also managed patients with haematological malignancies. I participated in an on-call rota for haematology with Guy's Hospital.
3. Consultant Haematologist, Royal Brompton & Harefield NHS Foundation Trust, 2006-2017, and Honorary Consultant Haematologist 2017-18 (post retirement). This post in a specialist heart and lung trust, involved less direct clinical management of patients, but I acted in a diagnostic and advisory capacity for all haematological problems in the trust, including complex haemostasis. I managed a small number of patients with hereditary bleeding disorders having surgical and other invasive procedures at the trust, in conjunction with appropriate Comprehensive Care Centres.
   From 2012-2017 I was also Director of Pathology for Royal Brompton & Harefield NHS Foundation Trust

I was a member of the UK Haemophilia Doctors' Organisation from 1997-2006, while Haemophilia Director at GRO-B.

Section 2: Responses to criticism of W1241

Question 4 of this Rule 9 request as sent to me states:

"At paragraphs 32 and 33 of his statement Witness 1241 states that you wrote to him and explained that Guy's Hospital did not have any records of the treatment he received there, and that because there was no direct evidence that he had received UK plasma, you decided that he had not been exposed to HCV. Please comment on this."

I would like to clarify that in his statement at paragraphs 32 and 33, Witness 1241 is referring to potential exposure to variant CJD, not HCV as stated in the question. I was aware that he did have HCV, and had already referred him for specialist second line treatment for this, which was successful in clearing the virus long term. I did not write to him stating that he could not have been exposed to HCV.

I am therefore addressing the question of potential exposure to variant CJD in this response. In doing so I have seen the exhibits enclosed with the Witness's statement, but I have not

seen the medical case notes. My response is based on my recollection of how I managed this issue at the time, and in the light of contemporary understanding of the risks.

The identification of variant Creutzfeldt-Jacob disease (vCJD) in the UK in 1996 led to concerns about the possibility of secondary transmission via blood and plasma. The risks were unknown, but a small number of symptomatic clinical cases associated with likely transmission by cellular blood components occurred. Given the exposure of patients with haemophilia and other bleeding disorders to plasma products, and the history of HIV and HCV infection in this population, there was major concern about the possibility of latent and/or clinical infection in haemophiliacs. Because clinical vCJD emerged predominantly in the UK population, rather than in others, it was considered that recipients of UK plasma products, rather than products made from non-UK plasma, were the group mainly to be regarded as at risk. This risk was considered to be twofold; first was the possibility that individuals might develop clinical vCJD, and second that asymptomatic individuals might pose a risk to public health by secondary transmission of the agent via surgical instruments, such as had occurred with classical CJD in the past.

A look-back exercise was therefore carried out to identify individuals who might be at risk, either themselves or for "public health purposes". This involved the staff of the Haemophilia Centres checking the treatment records of their patients and identifying those who had received UK plasma concentrates, within the time scale 1980-2001. I was responsible for carrying out that review in my role of Haemophilia Director at GRO-B . It was acknowledged that the information would not always be available, given the very long time-scale and the fact that patients were likely to have been treated at more than one centre. So the exercise was recognised to inevitably provide an incomplete picture. UKHCDO report 2014

Our records at GRO-B were comprehensive, and for most individuals we had what we thought were complete records of treatment. Once the records were checked the results were discussed with patients. Often this could be done in person at a review clinic, but in patients who were infrequently seen a letter would be sent inviting them to attend to discuss the issue. It was recognised that this was an extremely sensitive issue that could cause major distress. It was particularly difficult because there was no test available at this time to identify anybody who was carrying the prion infection, and there was the possibility of a very long incubation period. So no reliable reassurance or prognostication could be provided about this very serious condition.

Those patients who had clearly been given a UK plasma concentrate according to the records were given a notification letter informing them that they were "at risk for public health purposes" and that they should notify clinical staff of this fact before any invasive procedures, so that for certain procedures instruments could be single use, or quarantined after use, to prevent potential secondary spread of vCJD to another patient if instruments were re-used, normal sterilisation procedures not being considered sufficient to eliminate the prion. This created significant practical difficulties for haemophilia patients, as well as considerable worry and distress.

In addition to the potential general public health risk described above, some batches of plasma concentrates were identified as containing plasma from blood donors who had subsequently gone on to develop clinical vCJD. Recipients of these batches were regarded as being at potentially higher risk of developing clinical disease, but were treated in the same way for "public health purposes".

In the case of Witness 1241, there was a record available of treatment with a concentrate at Guy's Hospital in the early 1980s, but I did not have available which type of concentrate was used. If this had been commercial concentrate then it was not considered to be at risk as not made from UK plasma. I therefore enquired about what records were held at the St Thomas' Hospital Comprehensive Care Centre, as the Guy's centre was taken over by them. I was informed that records of the treatment used were not available. It seems that at some point this information was available as there is a record in the Witness' exhibits stating that this was BPL concentrate, which was a UK product, but to the best of my knowledge and recollection that was not in the records that we held, or were available from current records at the treating hospital. I therefore took the decision that we did not have sufficient evidence of exposure to UK plasma in this instance and in February 2005 wrote the letter to the Witness that concludes: "We do not therefore on the current evidence need to take any special precautions if you need surgery in the future".

In this situation I had two choices, either to label the Witness as "at risk for public health purposes" without direct evidence that he had received a UK plasma product, or to conclude that on *current evidence*, he did not need to be regarded as at risk. This advice could have been reviewed and updated in the event of surgery or an invasive procedure being required, or more information becoming available. This would not have been a decision I took lightly.

With the passage of time the limitations and outcomes of the look-back exercise are clearer. It was always known that the information would be incomplete. More recently the treatment

period considered to be potentially at risk has been changed from 1980-2001 to 1990-2001. So this Witness, whose only potential exposure to UK plasma was in the early 1980s, would no longer be considered at risk for public health purposes. I hope this is of reassurance to the Witness.

Section 3: Other Issues

1. [If there are any other issues in relation to which you consider that you have evidence which will be relevant to the Inquiry's investigation of the matters set out in its Terms of Reference, please set them out here]

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-C

Dated 25 June 2020

Table of exhibits:

Date	Notes/ Description	Exhibit number
	UKHCDO Annual Report 2914, p64-66	WITN3298004