Witness Name: William Wright
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INFECTED BLOOD INQUIRY

EXHIBIT WITN2287053

NOTES MADE / ANNOTATIONS ADDED DURING PENROSE INQUIRY.

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NOTE OF MEETING HELD ON 10 FEBRUARY 2000 IN SAH TO DISCUSS THE INFORMATION REQUIRED TO ASSIST IN THE EXAMINATION OF CIRCUMSTANCES SURROUNDING THE SAFETY OF SNBTS BLOOD PRODUCTS FROM HEPATITIS C

In attendance:

WHO IS MPS TOLKIEN?

Miss Teale, Head of Health Care Policy Division, SEHD
Dr Keel, DCMO, SEHD
Ms Christine Dora, Head of Health Care Policy Division, Branch 3, SEHD
Mrs Sandra Falconer, Health Care Policy Division, SEHD

Professor Chris Ludlam, Haemophilia Director, Edinburgh Haemophilia Centre
Professor Gordon Lowe, Haemophilia Director, Glasgow Haemophilia Centre
Dr P Cachia, Haemophilia Director, Dundee Haemophilia Centre
Dr Henry Watson, Haemophilia Director, Aberdeen Haemophilia Centre
Dr W Murray, Haemophilia Director, Inverness Haemophilia Centre
Dr M McColl, Royal Hospital for Sick Children, Glasgow

Apologies were received from:

Dr Angela Thomas, Royal Hospital for Sick Children, Edinburgh.
Dr I D Walker, Glasgow Royal Infirmary

1. **Miss Teale** opened the meeting with introductions and apologies and explained the background to the request for information from the Haemophilia Directors. She outlined the Minister's meeting with the Haemophilia Society and the Minister's undertaking to examine the circumstances surrounding the safety of the SNBTS products from Hepatitis C with particular reference to the Society's claim that Scottish patients were exposed to HCV longer than patients in England were.

2. **Miss Teale** thanked the HDs for the information previously provided which had given an indicative figure and she invited **Professor Ludlam** to provide an update of the situation. **Professor Ludlam** confirmed that further information could be supplied with the preface that it was the best the HDs could get. He confirmed that they had tried to weed out duplicates within the East of Scotland centres although further checks were required between East and West to ensure no double counting. The following details were provided:

Number of HCV positive patients currently alive by diagnosis living in Scotland:

East Coast Centres(Inverness, Aberdeen, Dundee and Edinburgh) = 125
(figure included 18 patients with von Willebrands disease)

Glasgow = 127
(breakdown as per letter of 13 August except 78 Factor VIII deficient patients instead of 88, also included 6 patients with von Willebrand's disease and 3 Yorkhill Haemophilia A patients.)

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Total number of HIV negative patients who had died in Scotland of liver disease since 1 September 1985 up to present date:

East = 3)
West = 12) It was stressed however that not all deaths were solely related to HCV.

Number of people treated for the first time in Scotland with a blood product (identifying how many treated with SNBTS products) during the period between 1 September 1985 and 30 June 1987:

East = 18 (8 treated with cryoprecipitate of whom 4 were known to be HCV negative and 4 were unknown, 10 treated with SNBTS Factor VIII or IX of whom 4 HCV+, 1 HCV negative and 5 unknown)

West = 13 (2 treated with SNBTS Factor IX are HCV neg, 1 with SNBTS Factor VIII and cryo known to be HCV+, 1 with commercial Hep C safe product and the rest were treated with cryo of which 3 are known to be HCV+.

Use of commercial products within the Centres during period 1 September 1985 to 31 December 1988:

Philip Cachia and **Dr Murray** confirmed that only SNBTS products were used at Dundee and Inverness respectively and **Dr McColl** advised that he was unaware of any commercial products having been used at Yorkhill.

Professor Ludlam advised that the following commercial products were used in the Edinburgh Centre:

Profilate - USA
Monoclate - USA

BPL 8Y was also used.

Professor Lowe and **Dr Watson** advised that checks had not yet been completed for Glasgow and Aberdeen.

3. **Dr Keel** reported that a major concern of the Haemophilia Society was that members alleged they were not given a clear explanation of the risks of treatment or the therapeutic options. Patients were tested without their knowledge and were not told of the results for some time and that during that time their partners were exposed to the unnecessary risk of infection. **Mrs Towers** explained that it was therefore necessary to try to establish whether there was a general policy on what patients were told and whether there an assessment of risk and if patients were given a choice.

4. **Professor Ludlam** explained that until the late 1980s the perceptions were that NANBH was a mild non-progressive condition, the first serious study on liver biopsy having been undertaken in 1985. **Dr Keel** confirmed this was also her understanding and **Dr Watson** advised that the only test for the virus at that time would have been by surrogate markers. He also commented that the clinician would

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have had to make the decision of whether to hand the patient a host of information or outline the benefits/risks of particular products.

5. **Professor Ludlam** pointed out that the driving force at that time was HIV and centres did not distinguish between HIV positive and HIV negative patients when giving advice about risk behaviour. All were treated the same and received the same advice. He advised that a circular about safe behaviour had been issued in 1985. **Professor Ludlam** also confirmed that the HDs liaised closely with the SNBTS on the development of new products. Guidelines issued in 1983, which advised the use of cryoprecipitate for mild haemophilia and then in 1984 advised the use of heat-treated concentrate. **Professor Lowe** pointed out that only 25% of patients in England received the 8Y product, which was subsequently found to be HCV safe. **Professor Ludlam** agreed to provide copies of the guidelines issued.

ACTION: PROFESSOR LUDLAM

6. **Dr Cachia** further explained that different products presented different risks and benefits and that the procedures and clinical staffing levels at the five Centres would have varied. The procedures followed now would be much more detailed because of the present state of knowledge. **Miss Teale** requested a breakdown of the staffing levels at the centre 1985 –1988.

ACTION: HDs

7. **Professor Lowe** pointed out that there was an awareness of Hepatitis at that time and every patient was treated with great care because of the risks of transmission. He explained that the policy was that patients would be informed they were being tested for Hep A, Hep B, Hep C and HIV and that the results would be discussed at their next appointment. Patients were encouraged to practice safe sex regardless of HIV status. He identified the Haemophilia Society publication 'Aids and Blood' which was issued in 1985 and preceded the perception that NANBH was serious and also mentioned British Liver Trust leaflets which were issued around that time giving advice on Hepatitis. It was agreed that the Department would approach the Haemophilia Society and the British Liver Trust to obtain copies of the relevant leaflets.

ACTION: SEHD

8. In view of the further claim by the HS that mild haemophiliacs were put at unnecessary risk by being treated with the SNBTS products when other products would have been safer and as effective **Miss Teale** asked whether it was possible to differentiate between mild and moderate haemophiliacs. **Professor Ludlam** explained that this could be possible and that case notes might show that in 1979 mild haemophiliacs received concentrates when DDAVP could have been used. This was however a matter of clinical judgement and patients were desperate at that time to be prescribed concentrate as this allowed them to treat themselves at home. He also explained that although mild haemophiliacs do not suffer spontaneous bleeds if they suffer trauma their situation was no longer mild. There was still a severe risk of death or disability if the bleeding was not stopped quickly and in many cases mild haemophiliacs presented with late bleeds which involved more treatment.

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9. **Professor Lowe** pointed out that most patients would have been infected whilst their predecessors were in post and asked whether it was necessary to contact them to make them aware of the situation. **Mrs Towers** explained that this was a factual information gathering exercise but that it should be borne in mind that the information might be used in future Court actions. **Professor Ludlam** also sought advice on whether HDs should be looking back to try to identify what had happened to patients whose whereabouts and status were unknown. **Mrs Towers** confirmed that Central Legal Office was representing the Trusts and SNBTS and that the HDs should therefore follow CLO advice on whether any further investigation or the tracking down of patients was necessary.

10. **Miss Teale** explained that it was the intention that a report be put to the Minister in March and confirmed that the following additional information was required from the HDs by 20 February:

- A definitive list of products used in that period;
- The statistics broken down by centre (after check to ensure no double counting between East and West centres);
- Details of the staffing levels at each of the Centres 1985 –1988;
- Copies of the Guidelines issued to HDs; and
- The number of patients treated prior to 1985.

11. **Mrs Towers** agreed to check with DH Solicitors on current position of legal cases in England and **Ms Dora** undertook to approach the Haemophilia Society and British Liver Trust for copies of their bulletins and advice leaflets.

12. It was agreed that a draft paper would be prepared and passed to the Haemophilia Directors and SNBTS for comments together with a copy of the remit of the exercise before being passed to the Minister.

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