

Witness Name: [REDACTED]

THE PENROSE INQUIRY

Witness Statement of [REDACTED]

I, [REDACTED] say as follows:

1. I live in [REDACTED] and am retired. Before I retired I was [REDACTED]
[REDACTED] I
am presently [REDACTED] years old.

2. I attended the meeting of Scottish haemophiliac patients on 19 December 1984 at the Edinburgh Royal Infirmary. The meeting had been called to discuss the impact of AIDS and my husband, who has haemophilia, was invited. The invitation indicated that a member of family could accompany my husband to the meeting. My recollection is that I ultimately went on my own to this meeting. I am not sure why my husband did not attend.

3. I understood that the purpose of the meeting was to provide information on the situation with regard to AIDS and the impact of AIDS on haemophiliacs. I have very little recollection of the actual meeting. I can, however, recall that it took place in a large lecture theatre at the Edinburgh Royal Infirmary and believe that it was attended by a reasonable number of people (I cannot recall how many). The atmosphere was, I think, relatively quiet and, as far as I can recall, Dr Ludlam and Dr Forbes represented the NHS. My recollection is that Dr Ludlam spoke for longer than Dr Forbes. As far as I can remember a social worker was present. I cannot recall how long the meeting lasted for. At the end of the meeting there was an opportunity for people in the audience to ask questions. I did not ask any questions at the end of the meeting.

4. I took handwritten notes during the meeting (in total four short pages). I was accustomed to taking notes during meetings as a result of my work, so this was something I would normally have done. I may have also wanted to write things down so that I could later discuss them with my husband who was unable to attend. I took the notes home and they were placed with my husband's papers where they remained until recently. My husband saw a request in the Autumn 2011 Haemophilia Society HQ Magazine for old copies of Haemophilia Annual Reports, Annual Reviews, The Bulletin or HaemoFacts from the 1980's and to get in touch with Dan Farthing, which he did. As a result of this Thompsons Solicitors sent a courier to collect all the papers that he had. Unknown to me the notes and the invitation to the meeting of 19 December 1984 were included.

5. I understand that the Penrose Inquiry has been provided with these notes and that a typed transcript has been produced (see annex to this statement). I can confirm that the typed transcript is a faithful reproduction of each of the four pages of my handwritten notes. I am unable to give any more details on the notes which I took. However, it would appear that the last page of the notes may refer in part to specific questions which were asked at the end of the meeting.

Statement of Truth

I believe that the facts in this witness statement are true

Signed..... 

Date..... 10/1/12

Annex

Typed transcript of [REDACTED] handwritten notes of the meeting of haemophiliac patients at Edinburgh Royal Infirmary on 19 December 1984

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 80 UK Dr Forbes
 7,000 World
 Causes Immune Deficiency
 CMV HTLV
 1) Immune Changes - tested when visiting hospital
 Lymphopenia ↓ T cells
 Reduced T4/T8 (helper suppressor)
 Reduces also No T4
 Skin tests Cutaneous anergy
 Reduced response to mitogen - activity
Further Study
 1) Further investigate supposed immuno deficiency in asymptomatic patients

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 Dr Ludlam
 HTLV III Type I may be associated with Leukaemia
 Other viruses may interact to cause AIDS
 Virus infused produces antibody – virus still present
 Heat treating factor VIII destroys virus
 Advice
 1) Semen) virus
 2) Needle prick) transmitted
 blood around – others wear gloves, apron
 Dental treatment – may transmit virus
Recommendations
 1) Make up own & administer own VIII
 IX
 2) If not family wear gloves & apron
 3) Cinbins
 4) Protective sheaths
 5) Close members of family don't give blood

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 1) Prepared to inform if have antibody
 2) Not having the antibody does not mean you have not been exposed to the virus
 3-4 years for implications of antibody to become known

Link HTLV3 & AIDS does not mean
cause & effect
State of ignorance - Research going
very fast
Cryoprecipitate made from smaller pool
but not as effective
Virus easy to kill
Genetic engineering of factor VIII
far away yet - not made from
plasma from Gene therefore No chance of getting any
virus
90% USA antibody
33% England
<10% Scotland

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Science Correspondent - Observer & Times
fact sheet being sent out to all Haemophiliacs
Batches 1 or several batches
half developed antibody
What are your plans for heat treating
factor IX - technically more difficult
1/3 less patients get HTLV3 antibody
BTS procedure - less likely to be with factor IX
Mild Mod Haem A treat DDAVP
Live virus HTLV3 used to test for Antibody
younger shorter incubation
older months - years
Saliva - Very late stages of disease
Not transmitted readily