

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392163

MEDICAL ADVISORY PANEL

NOTES OF MEETING HELD ON FRIDAY 11 MARCH 1994

- 1 Apologies
Dr Hay and Prof. Preston
- 2 Present
Dr Mayne, Dr Colvin, Dr Ludlam, Dr Tuddenham, Dr Lee, Rev Preb. A J Tanner, Mr Taylor, Mr Barker and Ms Richards.
Guest speaker – Dr Hann from Great Ormond St

- 3 Prophylaxis
The Chairman explained that the Society was in favour of prophylaxis for children but was looking to the MAP to give a clear lead on this issue that the Society could then promote. Dr Hann who was jointly responsible with Dr Hill for developing a protocol for the Centre Directors Organisation had therefore been invited to lead a discussion on prophylaxis.

Dr Hann explained that they were developing a protocol for prophylaxis for children which would act as guidelines for the standard management of haemophilia. It was not a trial but like any protocol it would be closely monitored. The protocol would contain recommendations for dosage levels, who should be treated etc. There was good evidence both from this country and abroad that prophylaxis prevents joint damage.

There was considerable discussion about the use of portacaths. Although some doubts were expressed about their use, especially in relation to the risk of infection, the general consensus was that it was alright to use them.

The protocol was due to be discussed at the next meeting of the Regional Centre Directors. It was agreed that the Society would use this protocol to promote prophylaxis for children. As part of this promotion Dr Hann agreed to write an article for a future edition of the Bulletin. In addition it was agreed that the Society would collect together material supporting the case for prophylaxis (including medical, financial and social reasons) which could include case studies and quotes from children and parents.

- 4 Zidovudine (AZT)
Mr Barker explained that the Society had been approached by the media on a number of occasions, most recently over the GRO-A case, for a view on AZT. A draft statement had been drawn up with the help of two members of MAP but it was felt that the full MAP should have the opportunity to discuss this issue and produce an agreed statement that the Society could use as and when necessary. The draft had been circulated and several members had submitted written comments.

Following a discussion a revised statement was agreed (copy enclosed). This would form the basis of the response to any media enquiry. In addition, members of MAP agreed to talk in more detail to the media if this was necessary.

Draft letter to Centre Directors near where Haemophilia Days are to be held

Haemophilia Days

Following their success in other parts of the country the Society is organising three more Haemophilia Days later this year. The standard format is a state of the art lecture on haemophilia treatment and care by a Centre Director, small group discussions facilitated by health professionals and plenty of opportunities for people with haemophilia and their families to share experiences and make new contacts.

We are planning to hold one of these Days in your area
on (date)

at (location).

We have found from experience that it is better to have the main speaker from outside the local area as this prevents any specific local issues dominating the day. We can then focus our attention on what we are all striving to achieve ie the best possible treatment and care for all people with haemophilia.

Enclosed is a provisional programme for the day. Further information will be sent as details are finalised. We would welcome your comments, particularly if you can think of an issue we ought to include that might meet a specific local need.

We have obtained sponsorship from the Henry Smith Kensington Estates for these Days and so we will only have to make a small charge of £5 to cover lunch.

We would very much like your support in promoting this event amongst your patients. I should emphasise that it is open to all people with haemophilia and their families not just members of the Society. We will be producing some leaflets which we would be grateful if you could make available to your patients. We also hope to produce a poster.

We very much hope that you will support the Society in this initiative which, on past experience is of considerable value to people with haemophilia and their families. Please do not hesitate to get in touch if you require any further information.

Best wishes

GB

5 Hepatitis

The Society is holding a pilot meeting on 12 March on hepatitis at which Dr Lee will give a presentation and answer questions. This meeting will help determine what further action the Society should take.

Dr Lee explained that there was limited information about hepatitis C and many unanswered questions. This was a problem for the doctors as well as the patients. She felt it would be helpful if there could be a joint educational meeting for haemophilia consultants and liver doctors.

Dr Ludlam explained that he felt that in some cases a liver biopsy was appropriate but there was no clear consensus amongst the members of the MAP that this was the case.

It was reported that different types of hepatitis C had now been identified and that this information was a good indicator as to whether the patient would respond to Interferon. This information could be used to ensure that Interferon, which was known to have side effects, would only going be given to those who were likely to benefit.

Reference was made to a recent court case where a person with haemophilia who had been infected with hepatitis C through the use of blood products was claiming medical negligence, on the grounds that he claimed that he had not been warned of the potential risk of hepatitis. The view of the members of the MAP was that there would be very few cases where there was any chance at all of a successful legal action on medical negligence grounds.

6 Information Exchange

Mr Barker reminded members of the MAP that at the last meeting they had agreed to send the Society copies of important articles on different aspects of haemophilia care. Mr Barker agreed to write to each member specifying which subject area he would like them to concentrate on.

7 Any Other Business

a) High purity blood products

In response to a question from Mr Barker the view of the MAP was that there was at present no evidence to suggest that blood products produced using ion exchange chromatography did not have the same beneficial effects as the monoclonal products.

b) Patenting of Human Genes

Dr Tuddenham reported that he had read the paper by the Genetic Interest Group (GIG) on the patenting of human genes and that he supported the line taken by GIG that the patenting of human genes should be opposed. The MAP endorsed this view and it was agreed that this recommendation be put to the next meeting of the Society's Services Committee.

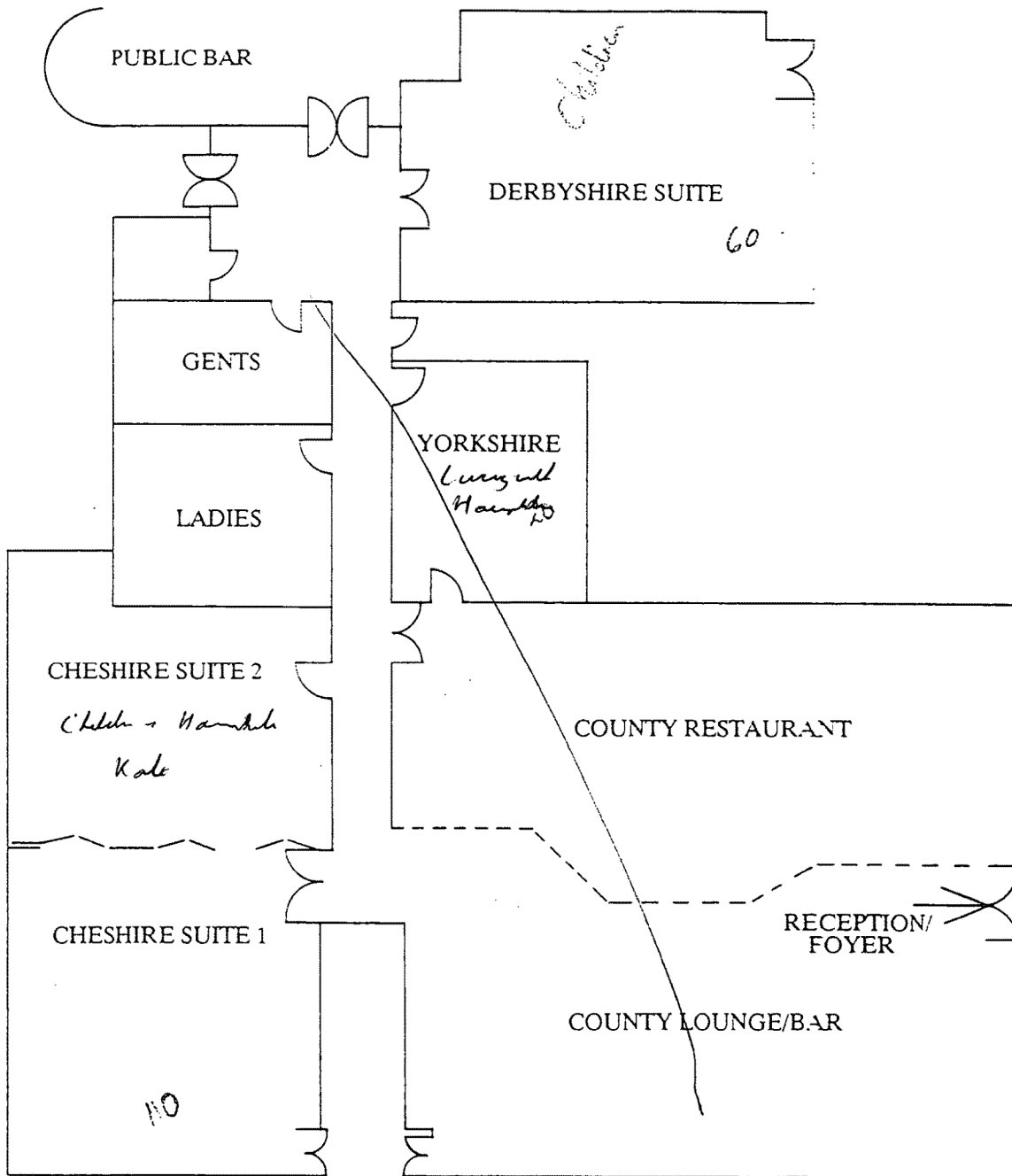
8 Date of Next Meeting

The next meeting was fixed for Friday 7 October 1994

GB 25.3.94

Conference & Banqueting Facilities

GROUND FLOOR LAYOUT



**The
Bramhall
Moat House**

+ 5 Synagogue
6 each.

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