

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

**INFECTED BLOOD INQUIRY**

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**WITN6392160**

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## NOTES OF MEDICAL ADVISORY PANEL MEETING THURSDAY 9 APRIL 1992

- MAP92.01**    Apologies for absence  
Peter Jones, Chris Ludlam, Eric Preston
- MAP92.02**    Centre Directors Blood Product Recommendations  
Dr Mayne explained that it was a consensus document based on the wide range of experience but that there was no perfect answer. The document reflected a feeling of change, especially in relation to HIV positives.  
A letter from Virginia Bottomley was circulated in which she indicated that funding should be made available to support the recommendations of the CDs. In response to questions MAP members felt that there was insufficient evidence to make distinctions between monoclonal and ion exchange products and that the licensing status was not of significant importance given that in the case of high purity factor IX there was only an unlicensed product available. The document was welcomed by the Society.
- MAP92.03**    Blood Products – Implementation  
This was proceeding across the board in Scotland and N.Ireland. Progress would be slower in England and Wales. The Society offered its support in promoting the implementation of the recommendations.  
The recommendations would be published in a forthcoming medical journal. In addition a paper on clinical guidance on haemophilia care was being produced for submission to the BMJ.
- MAP92.04**    Prophylaxis  
Dr Colvin said that the group most likely to benefit were children and that the Society should consider promoting this idea. There were practical problems in using prophylaxis with young children and not all (or their parents) would want or be able to cope. Unless a Centre had a critical mass of children it is unlikely that it would be able to offer prophylaxis.  
The CDO paediatric working group under Dr Hill and Dr Hann was developing a protocol for prophylaxis in children. It intended holding a meeting for the large number of interested CDs.
- MAP92.05**    Hepatitis  
Prof Preston was absent and unable to report on the work of the CD Hepatitis working group. The Society was producing a hepatitis leaflet for its members. A draft had been sent to several CDs and copies were circulated.  
It was suggested that although deaths from Hepatitis did not appear to have gone up this may have been hidden by deaths from AIDS.
- MAP92.06**    Cost/Benefit Analysis  
Dr Jones was understood to be preparing a paper using data from the States. The Society had itself not yet made any progress on this issue.
- MAP92.07**    Gene Therapy  
Ted Tuddenham introduced his paper for discussion. He talked about gene therapy for haemophilia in the context of the Clothier report. The following

points arose from the discussion:-  
 haemophilia could be a suitable case for gene therapy but we are a long way off;  
 technical problems to overcome - where put the gene; the way to get it in (retroviruses but a bit worrying because of HIV); need for animal models (vital because no wish to go straight to humans); theoretical possibility of unwanted side effects such as malignant change;  
 gene therapy being used in cancer patients but not yet haemophilia;  
 gene therapy does not eliminate transmission; pwh's daughter will still be carrier;  
 if successful and pwhs reached reproductive potential there would be steady increase in gene pool (and hence higher prevalence of haemophilia?)  
 if successful in small child (age 3?) could make all pwhs mild but would still need replacement therapy for surgery;  
 how much use to someone with damaged joints, hepatitis or AIDS?  
 as it is not a cure is it worth having? should it be called a cure?  
 how to get informed consent by child?  
 has got to be shown to be 100% safe;  
 all new work will be on fatal cases;  
 how would person cope?; experience in other areas suggest some people find it difficult to cope after a transplant;  
 Royal Free research is along these lines but appears to be claiming it is a cure;  
 scientific work will inevitably continue but must be honest about raising expectations.  
 Society's Policy Committee would be discussing this issue on 15th April with a view of responding to D of H by May 18th.

- MAP92.08      National Blood Authority  
 Further information to be sought after election
- MAP92.09      Health Circular (76) 4  
 Comments sent to D of H officials but delays caused by election. Need to follow up. CDs happy with reclassification of Reference Centres by Comprehensive Haemophilia Care Centres - figure set at 40 people. Centre Directors looking for machinery for designation - this must be linked to medical audit but not too closely. Benefits from audit will not be gained if it is seen as national accreditation process.
- MAP92.10      Medical Audit  
 Scotland done. Protocol for England being developed for circulation to Regional CDs
- MAP92.11      Haemophilia Society Strategic Plan  
 Ken Milne outlined the process and the need to work closely with CDs
- MAP92.12      Inhibitors  
 Mention was made of Cardiff trial for recombinant factor VII
- MAP92.13      HIV treatments

Mention was made of the Channel 4 programme putting people off zidovudine.

MAP92.14 von Willebrands Syndrome  
No developments to report

MAP92.15 Any Other Business

- a) Society requested that MAP members send them information eg articles on treatment. Mention was made of WFH clearing house.
- b) Support was given to the idea of preparing letter/note for parents of newly diagnosed children that existing blood products are safe.
- c) MAP members did not think the Society should give financial support to Centres to buy routine diagnostic equipment
- d) case in USA noted of 4 year old haemophilia boy being infected with HIV from 8 year old brother by parent using same needle. Response is close watch on cleanliness with home therapy.
- e) too early for feedback on new Hepatitis A vaccine

GB 10.4.92

**THE HAEMOPHILIA SOCIETY****MEDICAL ADVISORY PANEL**

Friday 15 November 1991 at 1pm (Buffet Lunch)

**VENUE**

Charitybase, 50, Westminster Bridge Road, London SE1

Tel: 071 721 7650

**A G E N D A**

MAP 91:01	Apologies for Absence: Dr E Mayne and Dr C Rizza	
MAP 91:02	Cost/Benefits of Treatment Study	DW
MAP 91:03	Prophylaxis	KM
MAP 91:04	Hepatitis	GB
MAP 91:05	Meeting with Secretary of State	AJT
MAP 91:06	Medical Audit in England and Wales	DW
MAP 91:07	Product Purity	KM
MAP 91:08	Future of MAP	DW
MAP 91:09	Strategic Planning	
MAP 91:10	Any Other Business <i>USA</i>	
MAP 91:11	Date of Next Meeting: 1 May 1992	

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Our Ref: DGW/pb

4 November 1991

1- AST + KM.

1.00 ?  
lunch

I am writing to CONFIRM that the Medical Advisory Panel meeting scheduled for Friday 15 November will be held at:

Charitybase  
The Chandlery  
50, Westminster Bridge Road  
London SE1

Tel: 071-721 7650

Among the items which will appear on the short agenda for the meeting will be the controversy surrounding high purity products; the future of the Medical Advisory Panel; hepatitis; prophylaxis and our own internal Strategic Planning process. The detailed agenda will be tabled on the day.

Yours sincerely,

c/b , *good of both*

David G Watters  
*General Secretary*

# MEDICAL ADVISORY PANEL MEETING

## Thursday 9 April 1992

To be held at:  
The Haemophilia Society  
123, Westminster Bridge Road,  
London SE1 7HR

### AGENDA

1:00pm Buffet Lunch  
2:00pm Medical Advisory Panel

*Jones*

MAP92.01	Apologies for absence	
MAP92.02	Blood Product Recommendations	Dr E E Mayne
MAP92.03	Blood Products - Implementation	Dr E E Mayne <i>in absentia</i>
MAP92.04	Prophylaxis	Dr B Colvin
MAP92.05	Hepatitis	Prof F E Preston
MAP92.06	Cost / Benefit Analysis	Dr P Jones (in absentia)
MAP92.07	Gene Therapy Consultation Paper	Dr T Tuddenham
MAP92.08	National Blood Authority	Any News / Views
MAP92.09	Health Circular (76)4	Dr E E Mayne / David Watters
MAP92.10	Medical Audit	Dr E E Mayne on Scotland ?England & Wales
MAP92.11	Haemophilia Society Strategic Plan	Ken Milne
MAP92.12	Inhibitors : Developments	Everyone
MAP92.13	Haemophilia and HIV : Treatments - Brief Discussion	
MAP92.14	von Willebrand's Syndrome : Developments and HP Products	Everyone
MAP92.15	Any Other Business	

*should be given to new diagnosis panel  
- safe now*

*Alert us to our work in published studies /  
developments*

*van Aken*