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THE INFECTED BLOOD INQUIRY

EXHIBIT WITN3429030

HSOC0010954

Minutes of the Medical Advisory Panel Meeting on Friday 27 April 1990 at the Kennedy Hotel.

Present: The Revd. Alan Tanner (Chairman), Dr Charles Rizza, Dr Elizabeth Mayne, Dr Chris Ludlam, Dr Brian Colvin, Dr Peter Kernoff, Dr Ted Tuddenham, Andy Cowe and Ken Milne.

In attendance: David Watters (General Secretary) and Jonathan Cooper.

Apologies: Professor A Bloom, Dr Peter Jones and Professor E Preston.

The Chairman opened the meeting by asking the members of the Medical Advisory Panel how they felt about the last meeting attended in part by Armour Pharmaceutical Co. It was generally agreed that it was not a "profitable use of time". It was suggested that if such a Company is invited again, they should present for 20 minutes over lunch with a 10 minute period for discussion. The Chairman concluded the discussion by adding that if representatives from pharmaceutical companies are asked to attend again, then the MAP members will be consulted first.

1. **Blood Products:** Ken Milne reported that for many years it had been Society Policy for the UK to be self-sufficient in blood products. In the light of high purity blood products from abroad and Recombinant Factor VIII, Mr Milne questioned whether this policy should be put under review. Mr Milne also asked if Centre Directors were under pressure to use 8Y and if they felt we should be asking for technical improvements of that product.

   The Medical Advisors unanimously agreed that safety was the priority in deciding which blood products to use. Dr Rizza felt that safety was of first importance and purity second. He therefore would continue to prescribe 8Y until it was proved that another product was safer.

   Dr Kernoff added that there was no evidence that one product was more or less safe than another.

   There was also general agreement that the principle of self sufficiency should remain a priority. Dr Rizza felt that self sufficiency would be unlikely as the UK is now already consuming 100m units of concentrate per year and the demand is increasing all the time. BPL will not, he felt, be able to meet this demand. This will particularly be the case if prophylaxis becomes a regular part of treatment. Children, he thought, could be placed on monoclonal product as they would therefore receive smaller doses.

   Dr Colvin felt it important to invest in the NHS. He was not convinced by monoclate compared to 8Y. He added that he felt any changes at Elstree needed to be "evolutionary rather than revolutionary".

   Dr Ludlam shared the views being expressed around the table and continued that BPL needs to make a decision as to the best product to pursue. BPL is also, it was mentioned, running more like a pseudo-commercial company - they want to know what the doctors and consumers want. This change in philisophy of BPL was warmly received by the MAP.

The European Directive on Blood Products, it was suggested also limited any change in policy on blood products.

The effect of the White Paper, "Working for Patients" was discussed. There was general agreement that there was not enough detail in the paper to know how it would actually affect care for haemophilia. What was not clear was the relationship between the purchasers, i.e. General Practitioners or District Health Authorities and the provider i.e. Haemophilia Centre Director's. There was general concern voiced over G.P's taking away patient choice by not allowing people with haemophilia to go to Centres of Excellence. Such Centres may be perceived as being more expensive. Choice over where to be treated should be left, it was agreed, to the person who knows what good or bad treatment is - the person with haemophilia.

2. **Livers and Hepatitis:** In Professor Preston's absence, this subject was not tackled in detail. Interferon, it was reported, appears to be effective, although more clinical trials need to be set up. The Society, it was considered, needs to encourage trials. HIV was not felt to necessarily jeopardise the trials.

   Interferon, it was reported, can upset patients. As it is injected subcutaneously this can also cause problems.

3. **U.K. Centre Directory - Progress Report:** Funding for the Directory has been received from BPL. The Directory can now go ahead with printing. It was agreed that it should be divided by region. All final details will be checked before going to press.

4. **1990 WFH Congress:** The meeting was told that WFH's hard work and expertise had brought about major shifts in U.S. Immigration Policy. There is also, the meeting was told, a Bill before Congress to repeal the immigration law. However despite those breakthroughs, it was felt that the human rights issue had not yet been resolved. Ken Milne added that he would be unable to attend the Congress unless <u>all</u> people with haemophilia and HIV can travel to the USA. This point was generally agreed upon by the rest of the panel.

5. **Europe:** The E.E.C. Directive concerned with blood products means that Europe cannot drop the objective of self-sufficiency. The fact that Elstree might sell its product elsewhere within the community was mentioned. Other European products might also be sold to us it was stated. For some people in society this has caused an ethical dilemma. How can you sell blood products from blood which had been voluntarily donated? A new organisation, the Association of Blood donors has been formed to protect the interests of blood donors.

6. **HIV Treatments:**

   AZT: It was believed that the MRC/Concorde trials of AZT should continue. The US trials, it was felt, were cut short too prematurely. There is still not enough known of the long term effects of AZT. It was felt that it might be, "a card you can play too early".

   The Medical Advisors generally prescribed the drug to people with consistently low CD4 counts - generally in the area of 200. Pentamadine is also offered to people with low CD4 counts.

DDI: DDI it was proposed might turn out to be a good alternative for people who cannot tolorate AZT. Although it was recognised that the MRC still need to set up a proper trial to confirm its advantages. Reports of DDI associated pancreatis caused concern to some doctors present. This seemed particularly threatening for people with haemophilia. It was also noted that the first 30 people treated with the drug developed diarrhoea.

In general, whilst discussing HIV treatments concern was raised over trial abuse. It was also emphasised that combinations of appropriate treatments should be started early. A number of drugs, it was considered were necessary for the control and prevention of infections. It was also felt that set guidelines should not be introduced until more was known about different therapies. The Medical Advisors were still unresolved about the difference that high purity factor VIII could make in slowing down HIV progression.

7. **Any Other Business:**

a. **Testing of Partners:** Although most Centres offer this service it can only be offered via the index person. Thus, contact with the partner is not easy and could be ethically dubious.

b. **Condoms:** It was considered should be available without charge or prescription.

c. **Safer Sex Guide:** The publication of the new Safer Sex Guide was announced. This would be on 2 June 1990 at the AGM.

d. The Problems over Hepatitis C were raised. A number of people are known to be Hepatitis C positive from blood tested from stored samples. This brought up the old ethical dilemam of how to inform people of a test result that they have not asked for.

e. The litigation cases were raised. Dr Kernoff felt there might be a backlash against the haemophilia community. People might start suggesting that people with haemophilia are too greedy. One Oxford newspaper also reported that if the RHA has to pay out compensation then they will have to close wards. This situation will be kept under close scrutiny.

8. **Date, Place and Time of Next Meeting:**

On 16 November 1990 at 1pm. Venue to be announced!