

THE INFECTED BLOOD INQUIRY

EXHIBIT WITN4504007

Minutes of the Health Sub Committee Meeting
Held on 10 September 2003, 1pm
Haemophilia Society

Present: Alex Susman Shaw (**AS**) (Chair), Bill Payne (**BP**), Dr Paul Giangrande (**PG**), Dr Brian Colvin (**BC**), Dr Has Dasani (**HD**), **GRO-B**, Roddy Morrison (**RM**)

In attendance: Karin Pappenheim (**KP**); Helen Courtney (**HC**) (minutes), Ruth Taylor (**RT**), John Morris (**JM**)

AGENDA

H66.01 Apologies were received from; Steve Wratten, Ian Hann and Chris Harrington

H67.01 **Notes of previous meeting held on 5 March 2003**

(**CH**) noted by email that under H55.01 the number of exposures is the usual at the Royal Free but exceptional compared to elsewhere. The minutes were accepted as a true and accurate record.

H68.01 **Matters arising from notes of previous meeting and not covered elsewhere on the agenda (to include: London service review, UKHCDO audit, CJD incident panel, NICE appraisal, research grants provided, port-a-caths) (Attachment 2, pink)**

H56.01 CJD incident panel report still awaited.

H58.01 Noted that the concluding report of London Service Review will be published in November.

H59.01 Noted that Nice guidance on pegylated interferon/ribavirin was in consultation and the Society had responded, liver biopsies were not included. However, the procedure hasn't changed; patients can still be treated without having a liver biopsy.

H62.01 Noted that Dr Mark Winter had asked the Society to support him in securing interferon/ribavirin treatment for his patients and we would be writing to the trust to urge them to fund this.

H63.01 The latest update on research grants was circulated with the papers

H64.01 The port-a-cath fact sheet is now complete and a copy was tabled at the meeting.

H69.01 Product safety and supply issues

a) Refacto concerns update – Dr Richard Littlewood and Anne Qua (Wyeth Europa Ltd)

The two representatives from Wyeth gave a presentation on Refacto covering changes in procedure for laboratories notified in July, new colour coded packaging and surveillance methods being used by the company. The complaints raised by individuals in Scotland about the product were discussed. It was noted that these may have been inaccurately reported in the press/media as the company's global safety team had reviewed 5000 patient records worldwide and found approximately 80 reports of lack of efficacy in Refacto and could not identify a cluster/pattern for Scotland. It seemed that only one case had been notified in Scotland, the society had not heard of other patient complaints about Refacto for elsewhere in the UK. It was noted that there could be complex factors involved in the treatment efficacy concerns raised by the Scottish patient(s).

a) Advate launch – update from Baxter

No date has been announced when the product will be available in the UK. It was noted that the cost of the product may be an issue.

c) Update on recombinant for all, progress in England (oral report)

KP reported that a meeting of the advisory group took place on the 9 October and that the national tender exercise is being concluded. It was expected that decisions would be taken at UKHCDO meeting in September in order that product could be obtained to enable roll out of recombinant. Recombinant should be available from 1 October to adults of 22 and over – although the upper age limit has yet to be agreed.

Professor Frank Hill (UKHCDO chairman) joined the meeting at 2.15pm by telephone conference call and reported that in finalising the national contract for recombinant it was important to avoid relying too heavily on any one manufacturer for supply given recent difficulties. It was noted that with regard to inhibitors, Novo 7 (the recombinant product) was not the only option and it was necessary to make a clinical choice for each individual patient. Professor Hill reported that letters would be going to PCTs and trusts in October to explain the recombinant roll out process. It was noted that 88 billion pounds may not be enough. A national contract for all product in year four was a possibility.

H70.01 Needs Assessment - to discuss progress report (attachment 3, blue)

The analysis of the results of the survey was discussed. It was noted that there is no other social/economic research to compare the survey with. It was noted that a face-to-face survey of patients is being conducted at Cardiff and that Wolfgang Scramm has also conducted some research in this area. It was noted that the survey will be compared with

the findings of the General Household Survey. There are many more people on the UKHCDO's database with mild VW than recorded on our survey.

H71.01 Women's Development project – to discuss progress report (attachments 4, green)

It was noted that we should write to Frank Hill about the current practice relating to referral of women with bleeding disorders to gynae team. It was noted that a booklet is being published by Ann Harper to educate gynaecologist about VW. It was suggested Michael Day and Celia Hall from The Telegraph are invites to the conference. **Action PG to email KP with the details.**

H72.01 Discussion of future membership of the group and topics for study/review (i.e. to confirm whether current members are happy to continue, consider topics that the sub group should focus on in future).

Everyone present in the meeting agreed that they would like to continue on the committee. Future topics for discussion included: women and bleeding, feedback from research projects, needs assessment survey, product supply and safety, treatment issues, home treatment and HIV/HCV.

H73.01 HIV and Hepatitis Coinfection Conference 2003 (attachment 5)

The update tabled at the meeting was noted.

22 bookings and 6 places from MFT have already booked.

H74.01 Any other business

HCV Compensation

The recent government announcement was discussed, in particular the medical issues that would arise if awards are dependent on a health assessment. It was noted that updates will be put on the Society's website. **KP** reported that further lobbying would take place to ensure that the scheme included the 212 people who died as a result of HCV infection.

DLA

BC reported that some patients are blaming consultants when they are turned down for DLA Benefits. There was a discussion of the information the Society provides to people with haemophilia about benefits, which indicates that entitlement to DLA is not automatic for people with haemophilia and that strong evidence of particular health problems/disability is required. The problem of short awards being made was noted which could lead to individuals losing DLA when entitlement is re-assessed. **BC** asked whether the Society could find ways of educating/informing patients/parents about the criteria of DLA.

VW and medication

RT asked whether women with VW who have a heart problem could be prescribed warfarin. It was noted that warfarin may be used for women with mild VW but is not appropriate for women with severe VW. It was also noted that a patient with high blood pressure and VW could generally take beta-blockers.

H75.01 Dates of next meetings in 2004

It was agreed that it would be more convenient to hold the meetings on a Tuesday. Suggested dates 2 March 2004 and 7 September 2004.