

NOTES OF A MEETING OF THE HEPATITIS TASK GROUP
held at 123 Westminster Bridge Road on Thursday 16 September at 4 pm

Present: Simon Taylor; Richard Dickason; David Watters

David had circulated some brief comments in advance on paper (appended to those notes). Current activity was reviewed on the basis of those notes. Discussion centred on other groups of patients who may be involved. Some work had been done on this and it appeared that a group of patients with Thalassaemia major could also be involved through their use of blood products. David was due to meet Alison Rogers from the British Liver Trust (BLT) in the next few weeks to take that point forward along with discussions on the usefulness of BLT information for our members on a formal plagiarised basis.

It was agreed after careful consideration that while there did not appear to be a basis for a generalised compensation campaign on the basis of presently held information, this should be kept under close review both in this country and with other WFH NMOs throughout the world. Further discussion on this appears later in those notes.

It was generally agreed that HCV affected around 3,000 pwh - a much higher number than with HIV.

The meeting moved to consider:-

Possible future activities

It was agreed that the most valuable roles which could be provided by the Society lay in the provision of accurate and up to the minute advice and information **and** an ongoing lobby to ensure the very best levels of treatment and care of people with haemophilia and hepatitis in any/all its forms along with support for those who are and become ill. The information aspect could be achieved particularly through our regular publications but also through the booklet on hepatitis prepared, and now finalised, by Richard. It was also **agreed that we should seek a copy of the disc for each Bulletin/Update from Health Network so that we can make our own print outs of articles subsequently.**

The hep booklet is currently with a potential funder seeking a grant to cover production costs which would enable the booklet to be placed in Centres throughout the UK so that it was easily and readily accessible to those who needed it most without necessarily having to contact the Society and 'identify' themselves.

Among the developments in treatment which we could monitor and report on were the development of vaccines; the effects of treatment; the effect of the use of HP blood products on those who are hep positive; etc.

Among the people who it was felt could be helpful were, of course, Professor Preston, Dr Christine Lee, Dr Charles Hay, Dr Peter Jones and Dr Mark Winter.

The meeting then went on to discuss recommendations for a **HEPATITIS AWARENESS CAMPAIGN FOR PWH**. After discussion a format was agreed whereby a series of meetings could be held at seven venues throughout the UK where medical and legal aspects of hepatitis would be presented at a three hour meeting which would also include time for Q&A's. Venues for the meetings could be:-

Perth; Craigavon, York, Manchester, Birmingham, Bristol, London - all at locations which were fully accessible to the disabled and with car parking.

'Home Players' would not be used, thereby giving those attending a sense of informal second opinion.

On the legal front it was agreed that, subject to approval by Committee B, a 'brief' should be compiled alongside lawyers: this could then be presented by a member of the Executive Committee.

Included in the package of recommendation would be that each information session should be attended by a member of the Executive Committee and a member of staff along with a medical expert. Meetings would be held at weekends on Saturday/Sunday afternoons.

The package should be announced, with a leader article, subject always to Editor's consent, in the December edition of The Bulletin. Dates, times, venues should be announced and people simply asked to 'turn up' with no prior booking necessary. Simple catering of tea/coffee should be provided. Fliers and posters should be made available in Centres and Centres staff co-operation sought in encouraging participation in the sessions.

It is anticipated that the above Awareness Campaign could be conducted at a cost of £3,500 on the basis of seven meetings each featuring three personnel with room and catering charges included along with occasional overnight costs.

Committee B are asked to:

- [1] ACCEPT this report**
- [2] APPROVE publication of the hepatitis booklet and the seeking of commercial sponsorship to enable that to happen**
- [3] APPROVE the proposal for a HEPATITIS AWARENESS CAMPAIGN as outlined above.**
- [4] COMMENT on other relevant sections of the overall review of our position.**

David G Watters

17 September 1993

CIRCULATION: As at 17.9.93 - HepTG, AC, Ctte B, AJT