



THE  
HAEMOPHILIA  
SOCIETY

The Haemophilia Society  
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## MINUTES OF THE HEPATITIS TASK GROUP MEETING

held on Wednesday 13th December 1995  
at the Ibis Hotel Euston, 3 Cardington St London

### Present

Andy Cowe ( Task Group Chairman), Dave Tonkin, Chris Hodgson.

### In Attendance

Graham Barker, Director of Services and Development, Mandy Cheetham, Hepatitis C Research Worker, Shanit Marshall, Information and Advice Worker, Evangelie Polyzos, Secretary and Administration Assistant.

### Apologies

Apologies were received from Paul Bullen. Andy Cowe asked Dave Tonkin to pass on from the Group's best wishes GRO-A

### 1. Minutes of meeting held on 26 September 1995

The minutes were accepted as an accurate account of the meeting.

### 2. Matters Arising

a) A number of questions were raised at the last meeting which Mandy Cheetham agreed to look into. She reported back that:

In a letter dated 13 / 11 / 95, the Health and Safety Executive stated that:

i) "HCV is not a notifiable disease and there are no plans to make it one". However subsequent information from the Public Health Laboratory Service Communicable Disease Surveillance Centre states that "acute hepatitis C infections would be notifiable as viral hepatitis ."

ii) The total number of people with hepatitis C is unclear. Accurate statistical information about death rates from HCV is not available as HCV is not always noted on the death certificate.

iii) There is no legal requirement on doctors to give patients information. However doctors have to demonstrate that to withhold information about a patient's diagnosis is in the best interests of the patient and that to disclose information could cause both physical or psychological damage to the patient.

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### **3. Campaign Update**

#### **a) EDM**

Graham Barker reported that the EDM had gone down on the first day of the new Parliamentary session and now had a total of 250 signatures supporting it.

#### **b) Hepatitis C Impact Report**

The group were told that the Hepatitis C report had been completed and published. Press coverage was gained in the Daily Telegraph. The report had been sent to all the MPs on the signatory list.

c) George Mudie MP had secured a half hour adjournment debate on 13th December which he would use to raise the report.

#### **d) Manor House Group meeting with Stephen Dorrell 18th December 1995**

Andy Cowe stated that congratulations were due to the Manor House Group for securing a meeting with Stephen Dorrell on the 18th of December. Dave Tonkin also thanked the Society on behalf of the Manor House Group for its help and support.

### **4. Research - Final Report**

#### **a) Discussion of Proposals to Society and Centre Directors**

Mandy Cheetham asked the group to look at her first report submitted to the October Executive and to give her some guidance and feedback with regard to priorities for recommendations to Centre Directors and the Society. Comments on how to make the report more focused and its priorities should be sent to Mandy Cheetham by Friday 5th January 1996. Her draft report will be considered at the Task Group's next meeting, and, the final version will be discussed at the Executive Committee meeting on 31st January.

### **5. Correspondence with Department of Health re Treatment**

The Group expressed disappointment at the reply from the Department. It was agreed that Graham Barker would reply asking for more information on what the Government was doing with particular reference to interferon, PCR Tests, counselling and public education. Asking Parliamentary questions should also be considered.

### **6. Litigation Update**

The Group discussed the letter from Graham Ross. It was agreed that if there was a good case for litigation, the Society should inform its members. Graham Barker would discuss this with Graham Ross and ask him to write a piece for the Bulletin, but warning him that this would be considered by the Executive prior to publication. Deas, Mallen, Souter would be given the chance to write a piece for the Bulletin giving their view of litigation.

## **7. Section 64 Project Grant**

### **a) 1995/96**

The Society will be reporting back to the Department of Health on the activities that took place throughout the year with a breakdown of the total costs incurred.

### **b) 1996/97**

The Society has applied to the Department of Health for funding in 1996/97. The application has been revised to ensure sufficient funding for a Hepatitis C Worker. The funds received from the Department will go towards publications on information and fact sheets about Hepatitis C, and support for self help.

Mandy Cheetham commented on the importance of ongoing research, as well as a need for constant monitoring and reviewing of the information and services available to Hepatitis C patients.

## **8. HCV Benefit Issues**

Shanit Marshall expressed the view that it would be unlikely that individuals would be able to obtain benefits on the merits of HCV alone.

However, unless a person was suffering so severely as a result of hepatitis C that they required help with getting around, or supervision / attention amounting to a minimum of an hour each day, they would only be likely to be more successful where claims for the mobility component of DLA were borderline cases, and the inclusion of information regarding the effects of hepatitis C on their mobility would strengthen the claim. She also outlined the possibility of individuals qualifying for the care component of DLA if they are undergoing Interferon Treatment for a period of over 6 months, and are experiencing increased care needs due to side-effects.

Shanit Marshall also stated that Therapeutic earnings could also provide a route to benefit of up to £44.00 a week for individuals who wished to work up to 16 hours a week, although their illness / disability prevented them from working full time. The GP of the applicant would have to provide a letter endorsing this.

It was agreed that information on HCV needed to be included in the haemophilia section of the Disability Handbook. Shanit Marshall would take steps to organise this. She would also produce a leaflet on possible benefits for people with haemophilia who have HCV, and how to strengthen DLA claims for HCV and applicants.

Continued discussion on benefits led to a decision that the Society should liaise with Mainliners and the British Liver Trust to exchange knowledge and discuss benefits in relation to HCV. Shanit Marshall would contact both organisations to discuss this.

## **9. Children and HCV - Discussion on Possible Activities**

Graham Barker explained that there were a number of issues relating to children and HCV that needed to be explored in more detail, such as their response to treatment and what information children should be given, and when. At present there is little information on good practice available on these issues.

Graham Barker had approached Schering Plough about the possibility of funding some work, for example a seminar, on this subject. Mandy Cheetham suggested that a paediatric liver specialist be contacted.

The issue of hepatitis C and its affects on children, was agreed to be added to the list of activities to be undertaken as part of the Section 64 Project but additional funding would also be sought.

## **10. Fact Sheets**

### **a) Format**

Mandy Cheetham asked the group to consider ideas for the format of the fact sheets and how they could be presented as a pack. It was suggested that a format similar to that of the BPL's 'New Horizons' would be appropriate. Another format suggestion was that the fact sheets be of A5 size and as leaflets, laminated, and presented within a folder.

The cost of producing these would be funded by the Section 64 Project Grant. Further costing details would be discussed with Mark Weaving of the Health Network.

### **b) Priorities**

Members of the Task Group were asked to suggest priorities for the fact sheets.

## **11. Any Other Business**

The group were informed of the disbanding of the Services Committee so that now recommendations from the Task Group would go directly to the Executive Committee. Minutes would also be distributed to all members of the Executive.

It was suggested that there be increased membership involvement within the Society's task groups to fully reflect the diversity of the Society's membership. The Group was asked to consider names of possible candidates to be put forward at the next meeting and for referral to the Executive Committee.

## **12. Date and Time of Next Meeting**

The next meeting will take place at 11.00am on Thursday 18th January 1996 at the World Mission Association. Please note change of time.