

## HEPATITIS CAMPAIGN GROUP

NOTES OF MEETING HELD AT 11.00 AM ON FRIDAY 6TH JANUARY 1995

- 1 Present  
AJT, ST, CH, RC, DC, GB
- 2 Meetings With MPs
  - a) Chairman to make own arrangements for individual meetings with Cormack, Marshall and Field
  - b) Meetings (one Labour, one Tory) to be arranged for other MPs depending on availability on 30 Jan, 31 Jan, 1 Feb.  
GB and DC to arrange and send letters  
Purpose of meetings is to give MPs an opportunity to tell us what they think. We present facts, some ideas but seek their comments on how we should proceed. Single sheet briefing to be given to them at meeting.
- 3 Clarification Of What The Society Wants
  - a) Financial help to individuals is one of 4 objectives; others are more research, more resources for treatment and public education.
  - b) More equitable treatment between HCV infected and HIV infected. In practice this may mean regular payments and access to cash fund (but not lump sum ex gratia cash payment) and only to those seriously ill (not all those infected) and support for dependents. Definition of seriously ill will need to be agreed and accepted by centre directors to trigger payment – this could be difficult to achieve.
  - c) Modification of Macfarlane Trust deeds to permit help to HCV infected people with haemophilia with additional funding to meet their needs; or creation of separate fund with similar pattern and administration.
- 4 Panorama – 16.1.95  
Understood that will focus on those who became infected with HCV from blood transfusion during period when test was available but not yet introduced in UK. This group (numbers unknown) could have case for compensation from Government. This may affect Society campaign. Society response to say our case is different and we are not at present seeking compensation from Government but are putting together case to present to Government for financial help. Prepared statement to be produced but not a press release.

5 Next Steps

- a) Briefing paper – to be updated to take into account figures, prognosis, how disease progresses, what it means to be ill from HCV, what the society is asking for, treatment recommendations (good progress reported from Eric Preston working party)
- b) Research into problems and needs of people with haemophilia and HCV as part of section 64 grant; discuss at Hepatitis Task Group.

GB 9.1.95



# THE HAEMOPHILIA SOCIETY

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## HEPATITIS C CAMPAIGN - PROGRESS REPORT

### 1. Campaign Group

It has been agreed that the Campaign Group will consist of the Rev Preb Alan Tanner, Simon Taylor, Chris Hodgson, Graham Barker, GJW (Rory Chisholm and David Candlin) and Mark Weaving (Health Network) as appropriate.

### 2 Meeting with Dept of Health

An informal meeting (ST and GB) was held with Tom Kelly at the Dept of Health to explain current position. Our concerns and wishes from Government spelt out in broad terms. This contact will be continued. Dept very happy with Society that not seeking compensation.

### 3 Briefing Paper for Parliamentarians

Jack Ashley tabled a question in Lords which was later withdrawn. Briefing note sent to Ashley, Baroness Masham and Baroness Jay. Alf Morris, John Marshall, David Alton and Joe Benton tabled PQs - copies of briefing paper sent to them and also Frank Field and Geoffrey Johnson Smith.

### 4 Information to Society Members

Briefing note sent to all members (28 November) clarifying what we want from the Government and giving current facts on HCV. Feedback positive.

### 5 Meeting with GJW 1 Dec 94

GJW suggested that important that Society make clear that we are making the running and it is our campaign (not MPs, journalist or lawyers). Letter to be sent to small number of friendly MPs before Christmas. This should suggest options (e.g. extend role of Macfarlane Trust or add on like Eileen trust) rather than ask for financial help and leave MPs to offer solutions. In new year (February) write to more MPs. By this time we must have more information on the nature and scale of the problem and clearer medical view on prognosis and treatment. Need to have medics ready to speak to press and infected/affected individuals prepared to talk to press. If possible a story in press before Christmas to keep issue on agenda.

### 6 Executive Meeting 1 De 94

Executive endorsed campaign strategy as proposed by GJW.

### 7 Meeting with British Liver Trust

Explanation of events and Society's current position given to Alison Rogers by GB. Agreed no problem in working together. Their major concern is research and awareness that HCV a bigger and wider problem than just haemophilia. They will press for:

**CARING FOR PEOPLE WITH HAEMOPHILIA**

- a) a general UK prevalence study
- b) a look back study to determine the natural history of hepatitis C
- c) a study to determine the value of single and combined therapies in patients at different stages of disease and with different genotypes etc.

GB 7/12/94

#### **LETTERS TO MPS**

In addition to MPs already contacted, letters have been sent (9/12/94) to the following MPs:

Winston Churchill  
Patrick Cormack  
Sir John Hannam  
Andrew Hunter  
Robert Key  
Archy Kirkwood  
Paul Marland  
Ian McCartney  
The Rev Martin Smyth  
Miss Emma Nicholson

We have also been approached by Barry Field MP offering support who has been contacted by one of his constituents.

Graham Barker