

**MEETING WITH EXPERTS AND CAMPAIGNERS TO DISCUSS
EVIDENCE BASE ON THE NATURAL HISTORY OF HCV
29 NOVEMBER 2012**

Note for those attending

Purpose

1. The purpose of the meeting is to provide an opportunity for the campaigners to put their concerns about the ill health effects of chronic hepatitis C infection to the experts, and for the experts to summarize the evidence they provided in Autumn 2010 and explain how they assess scientific evidence.
2. It is not to discuss payments or to negotiate changes to the Skipton Fund eligibility criteria.
3. Any aspects of the evidence base which are identified at the meeting that are thought to merit further consideration can be put to the Advisory Group on Hepatitis for detailed consideration and advice.

Organisation

4. Due to the relatively large number of campaigners now attending the meeting, and the limited time available, the amount of time available for each person to speak will be limited. In order to maximise the value of the time available, we will be handling the meeting in the following way:
 - At item 2, a representative of each campaign group will be invited to briefly summarise the key issues affecting their members. We would ask that each person does not prepare a long presentation, but simply makes key points and asks key questions.
 - At item 3, all attendees will be free to participate.

Venue and Time.

5. Richmond House, 79 Whitehall, London, SW1A 2NS. Starting at 2.00PM. The meeting will last 1 hour.

Attendance

Members of the 2010 expert group

- Professor Brian Gazzard.
- Professor Graham Foster.

- Dr Charles Hay.
- Dr Mary Ramsay.

Campaigner representatives

- GRO-A – Tainted Blood.
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- GRO-A – Contaminated Blood Campaign.
- GRO-A – Contaminated Blood Campaign.
- Chris James – Haemophilia Society.
- GRO-A – Haemophilia Society/Tainted Blood.
- GRO-A – Manor House Group.
- GRO-A – Manor House Group.
- Charles Gore – Hepatitis C Trust.

Officials

- Professor Martin Lombard, National Clinical Director for Liver Disease.
- Dr Rowena Jecock, Head of Policy, Blood Safety and Supply.

Agenda

- Welcome and Introductions.
- Purpose and running of the meeting.
- Item 1 - Overview of the clinical and scientific review in 2010.
- Item 2- Campaigners issues.
- Item 3 - Discussion of the main clinical issues raised by the campaigners.
- Summary.

Extra-hepatic conditions attributed to chronic hepatitis C infection by patient group representatives.

6. Patient and Campaign Group representatives have highlighted to the Department of Health a range of symptoms or extra-hepatic

conditions, which they consider are attributable to their chronic hepatitis C infection status. These conditions impact on quality of life of those affected, and for some, have prevented them from achieving their full potential at work, or forced them out of paid employment altogether. They have also highlighted some extra-hepatic conditions which reduce their life expectancy, and which they also attribute to chronic hepatitis C infection.

7. The main conditions and manifestations identified by patient representatives, are as follows:

Conditions that affect quality of life include:

- Neuro-cognitive impairments, including: depression, brain fog, memory loss, personality changes;
- Auto-immune disease;
- Diabetes;
- Chronic fatigue;
- Fibromyalgia;
- Musculo-skeletal problems, including arthritis, rheumatism, aching muscles, osteoporosis/osteopenia;
- Gastro-intestinal conditions such as gallstone disease and irritable bowel syndrome;
- The side-effects of treatment for hepatitis C infection, including depression;
- Co-infection with a range of different infectious agents. The interaction between these agents and the various treatments for them, has a cumulative debilitating effect.

Conditions that also reduce life expectancy include:

- Cardio-vascular problems, including pulmonary heart disease;
- Pulmonary fibrosis;
- Extra-hepatic cancers.