

# HEPATITIS C IN SCOTLAND

NOTE OF MEETING HELD AT ROYAL COLLEGE OF PHYSICIANS, EDINBURGH  
ON FRIDAY 20TH OCTOBER 1995

## Present:

Dr P Hayes, Dr E Follet, Dr P Molyneaux, Dr J Gillon, Dr C C Smith, Dr W Carman, Dr C Ludlam, Dr J McMenenim, Dr P Brunt (Convener).

## Apologies:

Dr N D C Finlayson, Dr P Mills, Dr D Goldberg, Dr I Kerr, Dr A Keel, Dr P Simmonds, Dr E McCrudden, Professor J D Cash.

The Group had before them the Report of the Working Party set up to consider the implication of hepatitis C in the context of Blood Transfusion Service "Lookback Studies", similar circumstances in Scotland at the behest of Professor Cash. It was acknowledged that hepatitis C was now of major clinical and public health importance and that Scotland was ideally suited in many ways to give leadership in research and clinical co-ordination, particularly in view of the presence of the Edinburgh University Virological Laboratories, the Institute of Virology in Glasgow, the SCIEH and the SBTS (which had led the way from the beginning in this field).

1. Dr Jack Gillon reminded the Group that approximately 3,000 patients with HCV were anticipated from the UK National "Lookback Study" with approximately 300 in Scotland. He outlined the present situation with regard to the "Lookback Studies". The smaller Centres such as Aberdeen and Inverness had almost completed the process of tracing. Dundee had not yet completed tracing. Edinburgh were approximately halfway through tracing. Glasgow still had the majority to trace and of course has the biggest problem, partly because of the very considerable numbers and partly because the Blood Transfusion Service is delegated down through Haematology Units. There were something like 1100 components to be traced. It was hoped that Greater Glasgow Health Board would be willing to pay for a full-time health worker. He anticipated that the final figures in Scotland would probably be about 250. The "Lookback Study" in England was in its very early days and only 2 or 3 Centres were underway.
2. Dr Jack Gillon, who is also a member of the Working Party in England (which has just been wound up), presented a paper from PHLS/CDSC proposing a national registry for hepatitis C infections with a known date of acquisition and of transfusion acquired hepatitis C infection. It was proposed that there would be a register of names of individuals so infected and serum would be banked. He personally felt that there were some considerable ethical problems that needed to be pursued and there was also a problem with confidentiality. The funding being asked for for this was in the region of £50,000.
3. Dr Gillon and Dr McMenenim indicated that informal plans were already underway for a registry/data base to be set up in Scotland between SBTS and SCIEH.
4. Dr McMenenim summarised some of the data now available on HCV in Scotland and in the various groups involved, including haemophiliacs and IVDA individuals. It was clear that the latter group represented a very substantial number of people in Scotland. He indicated that the Scottish Office had given the go-ahead for SCIEH to look at incidents/prevalence and, in particular, to assess rates in high risk individuals. A sum of something like £30,000 would be required for this study.

5. Dr Chris Ludlam outlined the situation with regard to haemophiliacs in Scotland - he has maintained a close interest in patients affected by blood products over recent years. About one third of his population of haemophiliacs also carried HIV as well and there was the special problem of multiple genotypes with poor response to treatment. The Association of Directors of Haemophilia Centres recently issued UK Guidelines for haemophiliacs with HCV.
6. Conclusions:
  1. The Group warmly welcomed the initiative of Dr Jack Gillon and his colleagues at IEH - Dr Goldberg and Dr McMenenim - in the setting up of a Scottish Data Base/Registry.
  2. A start should be made to explore the fruitful possibilities of research on the lines indicated in Section 6 of the Working Party Report.
  3. It was agreed that efforts would be made to identify sources of funding through the Scottish Office, the EEC and perhaps even drug companies involved in the diagnosis and treatment of HCV.
  4. To give added credibility and impetus to the importance of the subject it was agreed that steps would be taken to set up a Scottish Collaborative HCV Group and with this in mind a further meeting will be called early in the New Year to take this forward.
  5. The Convener would take steps to ensure that the Chief Medical Officer, Chief Scientist and College Presidents would be informed of the progress made thus far.