RESTRICTED-POLICY NQH23/1/19/1 (29)

NOTE OF MEETING HELD ON 1 SEPTEMBER 1999 IN SAH TO DISCUSS THE INFORMATION REQUIRED TO ASSIST IN THE INVESTIGATION OF CIRCUMSTANCES SURROUNDING THE SAFETY OF SNBTS BLOOD PRODUCTS FROM HEPATITIS C

In attendance:

Mr Michael Palmer, SEHD Dr Keel, DCMO, ME SEHD Mrs Sandra Falconer, SEHD

Professor Chris Ludlam, Haemophilia Director, Edinburgh Haemophilia Centre Professor Gordon Lowe, Haemophilia Director, Glasgow Haemophilia Centre

- 1. Dr Keel thanked the Haemophilia Directors for attending and advised that the purpose of the meeting was to clarify the validated information that would be needed from each of the Haemophilia Centres for the planned Ministerial briefing on 9 September. She explained that the Minister would meet the Haemophilia Society on 14 September to hear their concerns about the infection of haemophiliacs with HCV through treatment with SNBTS bloods products in the mid 1980s. The Minister had requested a report analysing what had happened at that time with an assessment of whether NHSiS' position could be said to be negligent.
- 2. She outlined what appeared to be the Society's central claim; that the NHS in Scotland was at fault in administering products which were not made safe from Hepatitis C for a period of over a year, contrary to assurances on safety, while in England a Hepatitis C-safe product was available. The critical period was between September 1985 (when the English product became available) and June 1987 (when Hepatitis C-safe product was made fully available in Scotland). Professor Lowe stated that Glasgow did not always get sufficient supplies of the SNBTS product, for all its patients, identifying a period of shortage during 1988/89 when some commercial product had to be purchased, but he confirmed no use of commercial products during the period in question.
- 3. Mr Palmer confirmed that the Haemophilia Society would focus on this critical period but it would be useful for the Minister also to have some background knowledge of the history of events and the scale of the problem throughout the whole of the UK. He considered that the main questions the Society would raise with the Minister would be to confirm whether or not the NHSiS was at fault and whether no-fault compensation could be paid.
- 4. Dr Keel pointed out that it would be necessary to fully investigate the circumstances and events during that time and to cost, based on a range of scenarios, the different types of assistance which might be awarded. It was therefore essential to estimate how many people would be eligible. Any follow up action taken by the

RESTRICTED-POLICY

Department would be in consultation with the other territorial departments on a UK-wide basis. She advised that the chronologies of events provided by BPL and SNBTS were revealing. PFC and BPL had deliberately chosen to pursue different paths in the development of heat treatment methods in order to cover more than one option and increase the likelihood of at least one plant coming up with a breakthrough. PFC did so for HIV and BPL then did so (in retrospect, unwittingly) for HCV.

- 5. Professor Ludlam suggested reference be made to published papers on the subject and in particular to a paper by Sarah Darby on the subject of liver disease related deaths in the UK published in the Lancet (? 1996).
- 6. Both Professor Lowe and Professor Ludlam confirmed that it was normal practice within their centres to inform patients of the result of a test if they were found to be HCV positive. Dr Keel would confirm that this was the procedure within the other Haemophilia Centres. In particular she was concerned about the case of a Dundee patient highlighted in the press coverage, who had claimed not to have been informed of his infection for a year after he was tested.

17

- 7. Professor Lowe reported that despite a shortage of staff to undertake this work he had made a start on validation of the figures for Glasgow and was currently checking the data on deaths to identify the causes of death. He would focus on HIV negative deaths and anticipated that it would take until 9 September to provide confirmed figures. He also hoped to be able to validate the figures for live HCV-positive patients within the next few days.
- 8. Professor Ludlam advised that there was a computerised UK database of haemophiliacs held in Oxford. Details were held by patient name and Centre, and Haemophilia Directors were invited to notify on an annual basis what treatment had been administered. He considered that this offered the potential to identify all haemophilia patients in Scotland who were treated for the first time during the period in question. This could pin point most of those patients who could be said to have been infected during the 'window period'. Dr Keel agreed to fax Dr Brian Colvin at the Royal London explaining the background and seeking information for calendar years 1985, 1986 and 1987 from the database. The information obtained would then be checked and validated by the individual centres.

ACTION: MR PALMER

- It was agreed that Professor Lowe and Professor Ludlam would provide details of:
- Number of HCV positive patients currently alive by diagnosis living in Scotland:
- Total number of HIV negative patients who had died in Scotland of liver disease since 1 September 1985 up to present date;
- Number of people treated for the first time in Scotland with a blood product (identifying how many treated with SNBTS products) during the period between 1 September 1985 and 30 June 1987; and

RESTRICTED-POLICY

Use of commercial products within the Centres during that period up to 1989.

ACTION: PROFESSOR LOWE, PROFESSOR LUDLAM

Sandra Falconer Health Care Policy Division 3 September 1999