AM15

PS(PH) meeting with Manor House Group
Wednesday May 15 2002

Present: Yvette Cooper, Parliamentary Under Secretary of Public Health
Mary Agnew (Department of Health)
Dr Vicki King (DH)
Charles Lister (DH)
Robert Finch (DH)

Sylvia Heal MP
Paul Goggins MP
GRO-A (Manor House Group)
Peter Mossman (MHG)
GRO-A (MHG)
Ollie Carruthers (MHG)
Carol Grayson (MHG)

Self sufficiency and David Owen issue

1. Discussion centred on the failure of the UK to become self sufficient in blood products during the 1970s especially after the then health Minister David (now Lord) Owen made recurring funds available for this purpose in 1975. The MHG detailed the serious concerns at this time about the quality and safety of conditions at the Bio Products Laboratory (BPL) which they felt was a mitigating factor in self sufficiency not being achieved. This led to the UK needing to import blood products from the US where it is suggested that the quality of screening was very poor and therefore, the blood that was imported came from prisons and 'skid row' donors which was more likely to be virally contaminated.

The Minister responded by informing the MHG that a meeting had been arranged between herself and Lord Owen, Lord Morris and Michael Connarty MP (Chair of the All Party Group on Haemophilia) to discuss the self sufficiency issue in relation to the funds Lord Owen provided for this purpose. The meeting was scheduled for late June.

The Minister also agreed to ask officials to look further at the papers from the 1970s to consider the possible safety problems at BPL during this period and to explore a Report from the Medical Inspectorate at this time, which was scathing about BPLs procedures.

Patients right to have been informed of risk of treatment

2. The MHGs view that clinicians and the medical community did not give haemophilia patients all the information they had at the time so that patients could make a fully informed decision about which treatment to use. This particularly refers to the change in treatment from cryoprecipitate (a treatment that was not heat treated and came from one donor) to pooled plasma (which was heat treated from donor pools of up to 20,000 and which did improve the quality of life of severe haemophilia patients).

   The Minister agreed to ask officials to refer to the papers from this period to get a fuller picture of what the known risks at this stage were. However, she was not aware of any evidence that clinicians deliberately misled patients about the risks of clotting factors. The seriousness of hepatitis C was not fully appreciated until at least the mid 1980's and this is possibly why clinicians might not have emphasised it as a risk factor, bearing in mind the beneficial impact of clotting factors on the quality of patients lives.

The moral issue/ no fault compensation

3. The MHG asked the Minister to reconsider the Governments decision not to pay compensation to those haemophilia patients who contracted hepatitis C through contaminated blood products. Although there were various strands of argument that the MHG were pursuing around compensation, a plea was made on moral grounds to compensate this group who had suffered so much. The MHG stated that it has been done before for people who contracted HIV through contaminated blood and more recently those with vCJD.

   The Minister stated that she was aware of the suffering of the haemophilia community on this issue and was deeply sorry for what had happened, but that the general principles that had been developed whereby compensation is only paid when the health service or an individual within it was negligent was correct and would continue. Compensation would not be paid on a no fault basis.

The Minister commented that successive Governments had look at this issue in detail and decided not to pay compensation.

Ignored warnings/public inquiry

4. The MHG stated that they felt warnings provided by some clinicians about the risks of using imported blood products were not taken seriously or acted upon so that the risks of haemophiliacs contracting hepatitis C was greater than it needed to be and that as a result a public inquiry was the best way for all the knowledge to be aired.

   The Minister responded by stating that the technology to make blood products free from HIV and hepatitis C, in sufficient quantities to treat all haemophilia patients in the UK was not available until the mid 1980s. Once it was, the NHS introduced it. Therefore, it was not believed that anyone's interest would be best served by a public inquiry.

Stigma surrounding haemophilia and hep C

5. The MHG reiterated their call that the haemophilia community faced discrimination and that this was another area where they had been let down by the Government.

   The Minister acknowledged that some people with hepatitis C may feel that they suffer social prejudice and discrimination and that this may, in part, represent a lack of public knowledge about the disease. In the forthcoming months, the Department would be publishing a national strategy for hepatitis C for consultation (which the MHG would be included in). As part of this process, we would consider what measures can be taken, including raising public and professional awareness, to reduce associated stigma.

Any other business

6. The MHG raised the issue of availability of the synthetic recombinant factor 8 treatment and why this was not available to all.

   The Minister stated that the Government are still considering the call to provide recombinant treatment for all and that a decision would be made later on this year.

   The Minister also asked the MHG to make contact with the All Party Group on Haemophilia, perhaps through the MPs present, as when the Department responds to the issues discussed they will do so through the All Party Group.