

NOTE OF A MEETING HELD AT RICHMOND HOUSE ON 10 SEPTEMBER 1997

Present

SoS

Chris Hodgson (Chairman Haemophilia Society (HS))

Tony Wilson (Chief Executive HS)

GRO-A Manor House Group)

Gordon Clarke (Vice Chairman HS)

GRO-A Trustee HS)

Dr McGovern (DH)

Ms Corrigan (DH)

PS/SoS (note)

Introduction

Secretary of State welcomed the representatives of HS and invited them to put forward their concerns.

Compensation issues

The Chairman began by thanking Secretary of State for agreeing to meet with the Society. He acknowledged the Department's contribution to the area as a whole in the shape of S64 grants and other funding.

The Chairman, Mr **GRO-A** and Mrs **GRO-A** outlined for Secretary of State the way in which Hepatitis C infection had affected their lives. They called for the establishment of a fund similar to the McFarlane Trust to assist sufferers. They envisaged that in scope and structure the two schemes would be very similar, providing a variety of benefits that would be cognisant of individuals' differing and changing needs resulting from the differing effect the infection might have on them. The MacFarlane Trust could administer such a scheme (as it had for the Eileen Trust) although there might need to be changes to the terms of the Trust to allow it to do so.

Secretary of State said that he had listened sympathetically to the Society's presentation. He would consider their points most carefully and would write to them shortly.

Recombinant Factor VIII

HS said that the availability of recombinant Factor VIII was patchy. In the South it was in common use; in the North and West it was less widely used. HS believed that the funding of recombinant Factor VIII should be funded by

central not local budgets. This problem demonstrated why haemophilia care generally did not sit well within the current NHS funding system and should be treated separately. Secretary of State suggested that the Society might like to make its views known to the Comprehensive Spending Review team.

The Society also suggested that the position on VAT and recombinant Factor VIII should be looked at. VAT is currently payable at full rate. The Society suggested it should be reduced to 5%. Secretary of State said he would consider this point.

The Society asked whether the Secretary of State would commit himself to a meeting with the relevant interest groups including UKHCDO to discuss funding questions. The Secretary of State was not persuaded of the need to hold a further meeting at this stage, but said that he would bear the suggestion in mind.