

Medical Advisory Panel

1. Introduction

- 1.1 It is some time since the membership and function of the Society's Medical Advisory Panel has been reviewed. Indeed, the panel itself has not met for at least two years. Given that the various Sub-Committees of the Board have been reviewed and re-constituted in the last year, it seems appropriate and timely to review the MAP and its future role. It is important that the role of the Health Sub-Committee is taken into account in this process to avoid potential duplication of effort. There is also the question of possible overlap with the new national Haemophilia Alliance.
- 1.2 A list of the current MAP members is attached for information. I have now had the opportunity to meet with many of them, and there is still willingness to be involved if required. At present the Panel is being used on an ad hoc basis by staff when queries about particular treatments or medical conditions arise.

2. Is there a continuing role for the MAP?

- 2.1 Looking at the current membership of the MAP, almost all have roles with the UKHCDO and are Comprehensive Care Centre Directors. There is an absence of nurses, of clinicians who are experts in HIV, HCV, hepatology or other non-haemophilia specialisms, or of professions allied to medicine such as physiotherapy. Equally, there are no members who are drawn from smaller haemophilia centres.
- 2.2 Hence, the first conclusion is that membership of the MAP could be expanded to include a more representative spread of expertise in the very multi-disciplinary field of modern haemophilia care. This would give us a wider spread of experts to refer to with queries on particular issues. A suggested list of new MAP members is attached.
- 2.3 This raises the question of the function of the MAP. Essentially, as the name suggests, its role should be advisory. As a patient organisation working in a complex medical field it is appropriate that we should have the broadest range of medical expertise on which to draw in our work. **However, whilst the MAP might be asked to advise on particular issues, the responsibility for formulating and making policy decisions would remain with the Chief Executive and Trustees.** Hence, it would not be the MAP's function, for instance, to frame the Society's policy on recombinants, although its advice might be sought.
- 2.4 Another role of the MAP would be to keep the Society in touch with developments in the field. This might mean keeping us briefed on latest research developments or equally feeding back information on what is happening in the NHS. Both of those functions are covered to some extent by the doctor and nurse members of the Health Sub-Committee, and the MAP would simply deliver more of that feedback and intelligence gathering on a wider scale.
- 2.5 A further key role for MAP would be to comment on publications produced by the Society so that we are confident in stating that all publications reflect best medical opinion at the time. This is common practice in most medical charities producing patient information.
- 2.6 The essential difference between MAP and the Health Sub-Committee would be that the latter has a role in formulating policy recommendations to the Board, and is an important part of the Society's governance systems. The MAP, on the other hand, has no formal role in our

governance and would function solely as a consultation forum. From my informal consultation with existing members of the MAP it appears that one of the difficulties in the past was that it was not clear whether the MAP was a decision-making body for the Society.

- 2.7 Another key difference would be that we would not expect the MAP to meet more than twice a year. For most of the year it would function as a 'virtual panel' with opinions being sought by post, e-mail, fax.
- 2.8 It is proposed, with the Board's agreement, to revise the membership of the MAP and invite new members to join as per the list suggested. It would be suggested, also, that a number of the existing members step down given their commitment to UKHCDO or membership of the Haemophilia Alliance or our own Health Sub-Committee, to make room for different Haemophilia Centre directors.

KARIN PAPPENHEIM
Chief Executive
12th March 1999

MEDICAL ADVISORY PANEL as of March 1999

Dr Brian Colvin MRCP FRCPPath*
The London Hospital

Dr Charles Hay MD MRCP FRCPPath*
Manchester Royal Infirmary

Professor Christine Lee MA MD MRCPPath FRCP
Royal Free Hospital NHS Trust

Dr C A Ludlam PhD FRCP FRCPPath*
The Royal Infirmary Edinburgh

Professor F E Preston MD MRCP FRCPPath
Royal Hallamshire Hospital

Dr E G D Tuddenham MB MBBS MRCP MRCPPath
Royal Postgraduate Medical School

Dr Paula Bolton-Maggs (Currently member of Health Sub-Committee)
Alder Hey Childrens Hospital

*All have roles with the UKHCDO and are likely to be much involved with the new Haemophilia Alliance.

PROPOSED NEW MAP MEMBERS

Other suggestions welcomed.

Nursing: Kate Khair (Great Ormond Street)
Nigel Hughes (HIV/HCV Specialist)
Sian Edwards (St Thomas')

Orthopaedics: Professor Leamont (Bristol)

Hepatology: Dr G Alexander (Cambridge)
Dr G Foster (St Mary's)
Professor Dusheiko (Royal Free)

HIV: tbc

Physiotherapy: tbc

Haemophilia Centre Directors:

WALES Peter Collins

N. IRELAND Elizabeth Mayne

SCOTLAND tbc

ENGLAND Frank Hill (Birmingham Children's)