

Meeting with Patient Organisations to discuss application process for Skipton
Fund 26 March 2004

Matters Arising

Present - Philip Dolan (Scottish Haemophilia Forum)
Charles Gore (Hepatitis C Trust)

GRO-A

Martin Harvey (Macfarlane Trust)
Jenny Jackson (Primary Immunodeficiency Association)
Gareth Lewis (Haemophilia Wales)
John Morris (Haemophilia Society)
Karin Pappenheim (Haemophilia Society)
Peter Stevens (Macfarlane Trust)

Richard Gutowski (DH)
Sue Patterson (Welsh Assembly Government)
Bob Stock (Scottish Executive)
David Reay (DH)

Apologies - Gerry Dorrian (Northern Ireland Civil Service)
Nigel Hamilton (Haemophilia Society, Northern Ireland)

Application forms

Suggested additions -

- Explanatory notes included on the application form including introductory paragraph indicating who might apply, who should be filling in different parts of form and how form will be used, what claimant does if unable to complete form because doesn't have the answers to all the questions;
- Further sub-divisions of forms;
- Footnote explaining applicants rights to see comments made on form by clinician
- Footnote defining what blood components are covered by 'whole blood transfusions'

Evidence -

- Explicit list of qualifying blood products
- Request that archive samples should be provided in cases where there isn't a presumption of the infection route. How will these be checked with blood authorities?
- Problems with accessing/retrieving evidence. -
- Which clinician best placed to complete form? First 'port of call' should be clinician treating/monitoring persons hep C.

Applications which are not clear-cut -

- First raft of application forms will screen out these applicants
- Suggested second tier forms which might include space to provide 'any additional supporting evidence' for claim
- Basis on which such applications should be referred to medical/appeals panel

Complimentary guidance

- Proposed guidance notes to accompany application forms – to contain FAQs, explanation of purpose of form, size of awards, eligibility criteria (definitions of PCR +ve/-ve, antibody +ve etc) and how form will be assessed/used by Skipton Fund
- Separate professional guidance for clinician for initial and second payment applications

Policy considerations

- Clinician fee for completing form
- Citizenship requirement *[Please note that since the meeting, Ministers have reconsidered this condition and it has now been dropped]*
- Issues around 29 August 'cut-off' date eg. who are eligible dependants?
- Management of 'minors'
- Waiver *[Please note that since the meeting, Ministers have confirmed that no waiver or undertaking will be applied to the scheme]*
- Inclusion and use of National Insurance number
- Eligibility of renal dialysis patients infected with HCV
- Eligibility of those who spontaneously clear acute/chronic virus

Engagement with voluntary organisations

- Telephone helpline - Skipton Fund would provide front line support
- National support network involving collaboration of patient groups – is this viable?
- Suggestion of external advisory group, consisting of representatives from patient groups, medical profession, patients etc to support Skipton Fund eg. on publicity, historical and treatment issues etc.

Communication strategy

- Publicising scheme – suggestions included briefing in CMOs Bulletin to alert profession, multi-lingual posters in GP surgeries, enlisting help of patient organisations, Skipton Fund website etc

Other issues

- Alternative method of payment for those without bank accounts
- Translation of application forms/literature into Welsh

Next steps

- Comments on application forms requested by Macfarlane Trust by 2 April
- Suggestions for guidance notes to accompany application forms requested by DH as soon as possible
- Follow up meeting planned to finalise application process

For discussion at next meeting

To include –

- Progress report
- Updated application forms
- Draft section of application form for second payment
- Communication strategy
- Appeals process
- Establishment of advisory group