I speak as chairman of the Insurance Committee of the European Advisory Board, which, as you know, is affiliated to the World Federation of Hemophilia.

From a medical point of view life is already difficult enough for the haemophiliac. Additional burdens are the everyday frustrations and annoyances which occur as a result of his condition. These often arise from relatively minor matters which present no real problem to the majority of the population. Insurance can fall into this category. Until fairly recently, it has only been by the usual persistence and determination needed to be displayed by the haemophiliac that he has been able to obtain the results he has wanted.

We shall be taking a look at life insurance first, followed by medical travel insurance. In both cases the United Kingdom’s results so far will be outlined. It is hoped that the UK experiences will be of assistance to other Societies which may still be meeting difficulties.

(1) Life insurance has been less of a problem than might have been anticipated. About 12 or 13 years ago it was very common for a haemophiliac wanting life insurance to be declined immediately without reference to his doctor or centre. Naturally, the haemophiliac proposer became disillusioned, depressed and bitter. This was the time when cryoprecipitate was the therapeutic material beginning to take over from plasma and, in the main, before the widespread use of concentrates. Life insurance underwriters often did not have up-to-date information about the rapid improvement in treatment methods and the consequent revolution in the lives of haemophiliacs. Life insurance, after all, is a commercial undertaking, and whilst the insurance industry does frequently display a social conscience, companies aim to make a profit. However, years ago there were some insurers willing to try to build up a specialised experience over a period.

(2) Usually, on receipt of a proposal form from a haemophiliac, they would call for a report from his family doctor, and he would also attend a routine medical examination at his haemophilia centre which would include a further report to the insurance company from the centre director or an assistant. The terms offered were higher than normal rates, but not usually too onerous. No proposals have been declined through my own sources. In many cases this must have been a great relief. The most frequent call for life insurance cover has arisen, and still does, when a young married man buys a house and wants to make sure that the outstanding debt to the lender would be discharged in the event of his death.

Clearly, gradually, with the increasing use of concentrates and spread of home treatment, further progress has been made. In the last year or two, where doctor’s reports are favourable, haemophiliacs have been accepted at normal rates – sometimes even in severe cases.
(3) One United Kingdom company has indicated that it would be prepared to consider life proposals from other European haemophiliacs. Proposals and other correspondence, including doctor’s reports would have to be in English, as well as being typewritten. Premiums and benefits would be payable in Sterling. At various World Federation Congresses, or in the literature, it has been said that well-controlled haemophiliacs conducting themselves in a reasonable manner have a normal life expectancy. It is hoped that this is true. If so, one of my committee’s tasks is to try to show that this is correct by means of properly validated statistics from unimpeachable sources.

(4) The problem of providing insurance cover against medical expenses whilst travelling abroad has been more difficult. Relating to medical expenses, almost all travel insurance policies exclude costs arising from a previous sickness or disease. Even where the exclusion is not obvious, in the event of a claim, a company could repudiate liability on the grounds of nondisclosure of a material fact, unless full details had been previously given on the proposal form and agreed. Fortunately, haemophiliacs are now much more mobile than could have been dreamed of 20 years ago. Concentrates, as available, can be very simply carried and stored temporarily so that travelling abroad becomes a routine event. The prudent traveller will take an adequate supply of concentrate on his journey, together with the WFH travelling guide and international card. Most European countries have reciprocal arrangements for the medical treatment of visiting foreign nationals. This certainly does not apply to the USA and other places sometimes outside Europe, where treatment costs can be very high indeed. These reciprocal arrangements, where they apply, are not entirely satisfactory because in some instances part of the costs have to be borne by the patient. Frequently, refunds of out-of-pocket medical expenses have to be obtained before leaving the host country, which may be impractical. Additionally, such arrangements usually are strictly for medical costs and do not take care of irrecoverable outlays such as cancellation prior to, or during the holiday, repatriation expenses (for the haemophiliac or member of his party), extra money for transport or hotel rooms.

After 10 years, via Lloyds of London, a special policy in the name of the Haemophilia Society has been arranged and has been working satisfactorily since May 1979. Contrary to most travel policies, in the relevant section, pre-existing disease is not excluded. Copies of the terms and conditions and rates are available here from me.

The need for this type of insurance has been clearly demonstrated from the number of members availing themselves of the special Lloyds scheme in the past 16 months. It is strange that travel insurance has never been presented as a serious problem by other European Advisory Board Societies.

On the other hand, member European countries have complained from time to time about the poor facilities available to haemophiliacs for life insurance. So that the exact nature of the difficulties being experienced by member societies could be ascertained, a questionnaire was circulated in the autumn of 1979. The questionnaire dealt with both life and travel insurances, asked for mortality statistics, if available, and requested comments on the nature of the problems which had been encountered.
(7) Just three replies were received from the whole of Europe which might mean, contrary to the British experience, that the problems are trivial, or non-existent. It is not believed that this is so at all, and in any event statistical evidence will be required in other contexts to help build up the total picture of haemophilia. Indications are that the statistics where available are sketchy in a form which may not be of great practical use or not easy to verify. Perhaps the new Central Information Centre at Heidelberg will be able to remedy this gap in our knowledge. Meanwhile if any of this audience is able to provide data which would help build up the statistical picture relating to haemophilia mortality I would be very grateful to hear from them. Equally well if anyone needs assistance on life or medical travel insurance I would be happy to help.