

Caring for people with bleeding disorders



THE
HAEMOPHILIA
SOCIETY
UNITED KINGDOM

Carol Grayson

GRO-C

19 July 2001

Dear Carol

Thank you for your letter of 5 July. You raise a number of different points which I will try to address here.

First, with regard to the aims of the campaign. As explained to members at the Solihull conference, and also in the Bulletin, the trustees and chief executive of the Society have given very serious and lengthy consideration to the future direction of the hepatitis campaign. This review has been extremely thorough, and has involved consultation by postal questionnaire with members and advice from legal, public affairs and medical experts. Such a review was essential in view of the government's continued rejection from July 1998 onwards of the Society's call for financial assistance for people infected with hepatitis. The Society has committed considerable resources to the campaign over very many years. Trustees have a responsibility to ensure the Society's resources are being used appropriately for the benefit of all our members, and have to be able to justify the commitment of resources for the campaign balanced alongside the other needs of the haemophilia community that the Society seeks to meet.

The outcome of the review is that the trustees have re-affirmed the commitment to the campaign; and have taken the decision to make a sizeable investment from reserves to increase the campaigning activity with support from professional public affairs experts Weber Shandwick. It was disappointing that at the AGM the Weber Shandwick team were not given a proper opportunity to present the very intensive new campaign strategy.

Contrary to the implication in your letter, this does not mean that the Society has departed from seeking *recompense*. The call for recompense continues to be one of our main campaign messages. The trustees have re-defined and clarified the aims in the light of experience and views expressed by members. We believe the campaign is now more inclusive in that our aim of achieving a public inquiry covers both those infected with HIV and those with HCV; as does the aim of securing recombinant for all, regardless of age or viral status. The Society will, of course, also campaign to ensure that all receive the best treatment, including access to interferon/ribavirin depending on clinical need.

I would assume that Haemophilia Action UK would support us in all those campaigning aims. Where you seem to take issue with us in on the matter of the 'hardship fund'. As far as the term 'hardship' is concerned, the Society has actually used this for many years. The Macfarlane Trust was originally set up as a 'hardship fund'. In 1996 when the Society published its first report on the impact of HCV on the haemophilia community by Mandy Cheetham, one of the recommendations was the setting up of a hardship fund.

In fact, there seem to be misunderstandings amongst yourself and some other members on this term, which you have interpreted as indicating 'means testing.' This is not the case. The Society has never defined a 'hardship fund' in terms of means testing. Other than stating that access to the fund would be dependent on *evidence of need*, the trustees have not taken any decisions about the way a possible fund would operate. As you know, the Macfarlane Trust and other schemes which exist abroad to provide financial help for people infected by contaminated blood, require medical evidence.

Work is ongoing at the moment to develop specific proposals for a hardship fund for people infected with hepatitis C in this country. We are studying closely the way other countries operate their schemes, and it is hoped that this work will be completed by October this year.

I hope this clarifies the Society's position. We obviously hope that you will support the campaign and can work with us to achieve our aims for all those who have been affected by the contaminated blood tragedy. To this end, we would like to invite you to a special briefing meeting on the campaign which the Society is holding in London on September 11. Details will be sent to you shortly by Karin Pappenheim.

I have noted the comments in your letter about one of our trustees George Levvy, and will be discussing these with him on his return from holiday in a week or so. I believe it is important to offer Mr Levvy the right of reply before forming any view on the matter; it is also fair to say that your own is not the only witness account I have been offered of the dialogue which took place outside the AGM.

With regard to your comments about the minutes of Society trustee meetings in 1991, these only represent a partial 'snapshot' of the continuing discussion within the Society on hepatitis. It has not been fully explained why you wish to have the 1991 minutes and how you had hoped to use them. Certainly we would not see the value in examining this minute out of context rather than as part of an ongoing process of review and discussion within the Society.

I hope to see you at the meeting in September.

Yours sincerely

GRO-C

 Chris Hodgson
Chairman

Cc Lord Alf Morris
Karin Pappenheim
Weber Shandwick