



## THE MACFARLANE TRUST

Alliance House 12 Caxton Street London SW1H 0QS

Tel: 0171-233 0057 Fax: 0171-233 0839

Our Ref:0330/AHCG

30<sup>th</sup> March 1999

M/s C Grayson

GRO-C

Dear Carol

Thank you for sending me a copy of the letter from Jim Cousins to Karin Pappenheim. I am glad that he is obviously taking an interest in those people who were co-infected with HIV and Hepatitis C, and will send him a copy of our recent Report to use as background if he should become active in the campaign.

As you know, our role is not that of a campaigning organisation, simply a means to provide some support to those who became infected with HIV through their treatment. However, the point I have made to you in our conversations, and which was, I know, made to members of the Haemophilia Society at their AGM last year by the Trust's Chairman, Alan Tanner, is that the Trust does not question the nature of illness when responding to grant applications. Grants are mainly given to registrants of the Trust for health related reasons, and Trustees and staff are as generous as possible, bearing in mind the need for fairness and consistency.

Whilst we have not been involved in the campaign for those infected with hepatitis C, the Trust has pointed out the additional problems suffered by those who are co-infected, in our Strategic Review Report. I know that when Trust representatives meet Baroness Hayman shortly, our Chairman will make a point of mentioning Trustees' growing concern about co-infection and the added difficulties it is causing for registrants. We shall continue to provide as much assistance as possible to all those registered with the Trust, of whom at least 95% are co-infected with hepatitis C.

I personally wish you every success in your fight for those infected with HIV and hepatitis C, for there is no doubt that the two viruses together are creating new problems for them. However, I have great sympathy with those who have haemophilia and hepatitis C because they have not received recompense of any sort, and many are becoming seriously ill now. It is important that you all find a way to work together and drive home to Government just what a serious and growing problem hepatitis C is to all those who suffer from it, whatever the cause.

With best wishes  
Yours sincerely

GRO-C

Ann Hithersay  
Chief Executive



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Jim Cousins, MP

GRO-C

Dear Mr Cousins

M/s Carol Grayson of [GRO-C] has copied me your letter to Karin Pappenheim of the Haemophilia Society, following your recent meeting with The Society about their concern for people with haemophilia who contracted hepatitis C through their treatment with contaminated blood products.

As you may know, The Macfarlane Trust was set up by Government in 1988, following a campaign by The Haemophilia Society on behalf of those with haemophilia who had contracted HIV through contaminated blood products.

During 1998, the Trust carried out an in-depth review of the 480 survivors from the original group of 1239 who became infected, in order to learn more about how they were coping with the effects of living with HIV ten years after the Trust was set up.

I enclose a copy of the Final Report of our Review. You will see that over 95% of our registrants are dually infected with HIV and hepatitis C. There is little doubt that hepatitis C is of growing concern to many of them because of it's effect on those with haemophilia, and because of the interaction between treatments for HIV and hepatitis C on livers already damaged by one or other infection.

We welcome your interest in the Haemophilia Society's campaign, and whilst the Macfarlane Trust is not a campaigning organisation, we are happy to provide information to support what is relevant to those registered with the Trust.

With best wishes

Yours sincerely

GRO-C

Ann Hithersay  
Chief Executive

*cc Carol Grayson*

# THE HAEMOPHILIA SOCIETY

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Patron: HRH The Duchess of Kent

Carol Grayson

KP/sr399/30

GRO-C

29 March 1999

Dear Ms Grayson

I write to follow up our previous correspondence and in the light of discussions at last week's Board meeting.

Having received your letter of 13<sup>th</sup> March and considered your comments carefully, it seems that there has been a communications breakdown. I accept your written assurance that you did not tape-record our conversation. At the same time I take that also as an assurance that you would not do so in future without first making it known that you wished to record the conversation with a staff member. Obviously we recognise that from time to time people may wish to record information given when they contact the Society. However, the Trustee Board were of the firm view that permission should be asked first if someone wishes to tape record a conversation and there should be an agreement between both parties as to the purpose of any recording. A statement to this effect will be issued in the Bulletin in order that members and users of the Society's services should be aware of this policy. It is my understanding that the Macfarlane Trust intends to make a similar statement.

With regard to the many other points your letter raises about the Society's response to people with HIV/HCV co-infection, we are very strongly committed to providing support through information, advice and other services. Both our Hepatitis Worker and HIV Development Worker are there to provide that support. The Society has also worked very closely with the Macfarlane Trust on its review of the needs of registrants, most of whom are co-infected. You may by now have seen a summary of the review from which it should be evident how seriously the Society and Macfarlane Trust take the issue of co-infection. The report of the review has now been submitted to Government and a response is awaited. Meanwhile, the Society, the Trust and Birchgrove Group are working closely together to ensure implementation of the recommendations, most of which directly concern people who are co-infected.

As far as the campaign for people with haemophilia and HCV is concerned, I am sorry that there seem to have been misunderstandings about the Society's purpose. I believe you have now heard from your MP Jim Cousins, who attended our recent briefing, and I am pleased that he went away from that meeting reassured about the Society's stance in relation to co-infection. Mr Cousins himself pointed out during the meeting that the Society's briefing materials clearly refer to co-infection. I should mention also that Lord Morris, who chaired the meeting, was fully briefed about situation of co-infected people, and as you may be aware, the Society previously ensured that this was included in his speech during the Lords' debate last June.

I hope this resolves the number of different concerns raised in the course of your recent contact with the Society. Should you wish to use the Society's information and advice services in future, please feel free to do so.

Yours sincerely,

GRO-C

Karin Pappenhorn  
Chief Executive

*Caring for people with haemophilia and related bleeding disorders*

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