05/03/2000.

GRO-C

Re -Hepatitis C. A SECOND Campaign For A SECOND Injustice

Dear Jim Cousins, (and other interested MPs),

You will probably be aware that a debate on haemophiliacs and hepatitis C is being held on Tuesday 7th March in the House Of Commons. Karin Pappenheim of the Haemophilia Society has sent out a two page document on the subject to all interested MPs. However as usual there are some serious omissions regarding co-infection which makes the information imbalanced! I would be grateful if you have the time could you attend this debate if not could you make this information available to other MPs so they are not prevented from seeing the whole picture. I have listed a number of important points for inclusion in the debate.

1. To highlight the fact that the overwhelming majority of hepatitis C related deaths are from the co-infected group, (those with HIV and hepatitis C.) 8 co-infected haemophiliacs died of liver -related problems in one month following Christmas.
2. 95% of haemophiliacs with HIV now have hepatitis C. We ask for a public inquiry as to why this has happened. Will it be only a matter of time before we find out that there is CJD in the blood supplies ? In order to stop such disasters happening again we need to find out why they happened in the first place.
3. Liver failure caused by hepatitis C is now the leading cause of death in HIV positive people in America and Europe.
4. I refer you to the Haemophilia Society's document where the "Social economic impact of hepatitis C infection "is discussed . Co -infected haemophiliacs are experiencing all these problems for the SECOND time, first they experienced these problems due to HIV, they had only just begun to learn to live or die with HIV when they were diagnosed as having hepatitis C. This is why co-infected haemophiliacs who have been largely ignored by the Haemophilia Society have set up a SECOND campaign calling for a SECOND recompense pay-out for a SECOND injustice.
5. The document discusses denial of treatment but what the Haemophilia Society fails to state is that for the vast majority of co-infected haemophiliacs treatment is not even a viable option.
6. What are the particular problems of the co-infected? In a sentence the two viruses do not get on together. Co-infected haemophiliacs face the problem of QUADRUPLE JEAPODY - That is they face the individual problems related to first HIV then secondly hepatitis C. On top of that there is the third problem of the serious effects of HIV treatment for example on the liver because of the presence of the hepatitis C virus, often resulting in liver toxicity. Finally we come to the fourth problem of there not being suitable treatment for hepatitis C infection in HIV positive haemophiliacs because they often have such poor immunity in the first place and treatment such as Interferon , Ribavirin could kill far more then cure. If this sounds confusing that is exactly what it is, any treatment that is used on the co-infected is very much in the experimental stage. Co-infected are usually not considered for liver transplants because the risks are much higher than for those haemophiliacs with hepatitis C alone.
7. Haemophiliacs with hepatitis C bleed more, they may need more joint operations which can again be affected by both viruses, one example is the effect of anaesthetic on the liver and the problem of operating on someone who has a low immunity due to their HIV, the risk of infections etc.
8. The Irish Government have compensated all their haemophiliacs whether mono-or co-infected, we now have the situation where one gentleman, a co-infected haemophiliac and registrant of the Macfarlane Trust has been awarded a pay-out because he received plasma whilst visiting Ireland. This

is wonderful news and rightly so. This gentleman will receive around £300,000, the other 4,800 haemophiliacs in the UK have received nothing for hepatitis C, neither have the widows and dependants. It is worth noting that this was by no means amongst the highest of the awards.

9. It is a sad lack of communication and bad manners from the Haemophilia Society that they failed to make the Macfarlane Trust aware that they were going to publicly state that they were asking for the remit to be extended to cover those who have hepatitis C and not HIV. As the partner of a Macfarlane Trust registrant and member of the Macfarlane Trust Joint Partnership Group I fail to understand how this idea was not discussed on Monday 28th February when the Group met up with a member of the Haemophilia Society with hepatitis C on the agenda and that The Macfarlane Trust were only informed of this debate on FRIDAY 3rd March.
10. I refer you to the "Financial Help" part of the Haemophilia Society's document. As I stated apart from the exceptional case above no haemophiliac in the UK has received any recompense for hepatitis C infection. The Macfarlane Trust was set up specifically for haemophiliacs infected with HIV which is stated in the deeds. CONTRARY TO MYTH IT RECEIVES NO MONEY WHATSOEVER FOR HEPATITIS C. If a second trust was set up under the Macfarlane umbrella it would need to be a specific Hepatitis C Trust with deeds stating this so both mono-infected and co-infected were eligible to apply as we must not forget that for over 400 people this is a SECOND injustice requiring a SECOND recompense pay-out as has happened in Ireland and Canada and the setting up of a SECOND trust.
11. Anyone wanting further information on the problems of co-infection should e-mail me on GRO-C