05/07/2000.

Haemophilia Action UK
GRO-C

Tel: GRO-C

FOR THE ATTENTION OF THE CHAIRMAN, THE CHIEF EXECUTIVE AND ALL TRUSTEES OF THE HAEMOPHILIA SOCIETY

Dear Chris,

We write with great concern over the Society's decision to campaign for a "hardship" fund as part of its recently relaunched HCV campaign objectives. Lord Morris has stated that what has befallen the haemophilia community is the "worst medical treatment disaster in the history of the NHS" and yet the Society feels this plight is only worthy of a hardship fund!!!!!

At no time have members been balloted on this issue and presented with alternative options such as recompense on a parity with Eire, surely you could not have failed to notice the wave of anger and protest at the AGM amongst many virally infected haemophiliacs who feel their opinions continue to go unheard! The HCV questionnaire sent out to members last year certainly DID NOT raise this very important issue and since the original campaign was launched in 1995 the wording until recently has stated RECOMPENSE. Many haemophiliacs and their families have worked tirelessly with their MPs calling for recompense and now we ask ourselves why our own national Society is selling us down the river! You used one such MP and his EDM on the front of the Bulletin magazine, Fraser Kemp is NOT calling for a hardship fund and this EDM came about largely due to the hard work from Ollie Carruthers NOT the Society.

We were also disgusted at the Society's attempt to claim that it was largely their efforts that secured the Meridian documentary. Colette Wintle worked very hard alongside Holly Lewis to persuade Holly of the value of such a documentary as an expansion of previous features on haemophilia issues. We were also able to provide Holly with detailed background information with regard to chronology, history and the David Owen statements featured on World In Action, which we have circulated widely again this year. The relationship with our media contacts is ongoing with further coverage planned for the near future. With regard to up and coming media projects we will be stating that the Society is NOT representing the views of grassroots haemophilia groups and is out of touch with many of its members. This was in fact stated to Lord Hunt at a 90-minute meeting, which took place recently.

Haemophiliacs are seeking recognition of damage with a comprehensive recompense package such as that which has been achieved through the efforts of the Eire Haemophilia Society. A hardship fund based on financial need as described in Society literature would not recognise damage and would create huge financial inequalities particularly if means tested. It is conceivable that you could have an HCV haemophiliac/person with bleeding disorder who is asymptomatic on a low income who because of receiving state benefits could access a hardship fund whereas a person who is in end-stage liver disease but receiving a small works pension may receive nothing from such a fund. Those of us sitting on the Macfarlane Trust Joint

Partnership group are only too aware of the difficulties with similar systems despite recent efforts to have more equality of payments to registrants.

Phil Dolan, trustee, very kindly introduced a group of members to fellow trustee Mr George Levvy at the AGM so that we might seek his opinions on a hardship fund. (The AGM literature provided trustee profiles and encouraged members to take the opportunity to meet with trustees.) We took this opportunity and we must say we were appalled at Mr Levvy's attitude towards members, which we felt was both arrogant and insensitive. He appeared to have no comprehension of the suffering endured by many within the haemophilia community and told members to "forget the past." This in itself does not marry with the Society's aim of a public inquiry, which would among other things provide a detailed examination of practises / decisions / mistakes of the past in order to learn for the future. Many haemophiliacs who are ill and dying find it very difficult to foresee any future!

Mr Levvy is of course entitled to his opinions but after a few minutes conversing with our group it was clear that he has little understanding of the very difficult circumstances many HCV/HIV positive members find themselves in. He appeared aggressive and dismissive of members' opinions. On leaving to meet his family we reminded him that he was very lucky to have a family to go home to unlike some members who have lost one or more family members to viruses without ever receiving any form of justice. We were confronted by Mr Levvy drawing a finger across his throat in a slashing motion with the words "What do you want me to do, cut my throat!" We were astounded at this totally unprofessional outburst witnessed by a number of people. This incident imprinted on our mind remains deeply distressing at a time when on top of Peter's increasing health problems we now receive a letter from a hospital trust stating that organs were removed and retained without permission, taken from his brother Stephen on his death from HIV, yet another example of withholding of information from the haemophilia community!

We believe that the Society is making a grave error with regard to their stance on a hardship fund and should reconsider this decision. What we find totally hypocritical is that one of the Society's own trustees who is supporting a hardship fund for the masses has approached my partner's solicitor on the back of OUR case and evidence to fight for RECOMPENSE for HIMSELF.!!!!!! Surely this is a conflict of interest if he believes so strongly in a hardship fund for the haemophilia community. This attitude we feel is typical of the Society's double standards, a Society which should be fighting for a recompense package for ALL.

We discussed the meeting with the solicitor with the trustee himself over the phone and had asked our solicitor to be informed of all clients who would be utilising OUR case and OUR information, which is perfectly reasonable if people are using OUR material. This does not breach confidentiality as our solicitor is interviewing clients on that basis, and the concept of certain shared information is put to them at the initial appointment along with the fact that Peter has the test case. Anyone who feels they can not accept this is of course free to try his luck with a case elsewhere. All the current HCV cases, which our solicitor is handling, are as he states purely as a result of OUR years of effort to establish a case and putting infected haemophiliacs in touch with him, had we known that this person was fighting for a hardship fund we wouldn't have bothered to pass on our solicitor's details!

We wish to commend the integrity of one trustee Phil Dolan who despite fierce opposition has had the courage to stand up for what he believes is a better option and in keeping with what many members want, RECOMPENSE. We hope Phil will not be ostracised in the way members have been over the years for challenging the opinions of the Society. This would be a matter of great concern to members and we are sure with the Charities Commission! We note that in the Weber Shandwick presentation some activism was encouraged with regard to the campaign we wonder how the Society plans to move forward on this issue when even a difference of opinion on campaign objectives seems to be viewed as a major threat!

On a final matter ourselves and members of the press have STILL not received information on the names of the "experts" who gave the opinion that hepatitis C was NOT an issue for the Society in November 1991 (see old minutes.) We have approached both yourselves and Weber Shandwick for this information, which surely should be in the public domain. It concerns us that even in 1994 despite our many calls to the Society hepatitis C still wasn't considered an important enough issue on which to campaign. We also received this same attitude towards co-infection a few years ago despite our efforts to get the Society to take notice of the research papers we were reading on the subject at that time! The Haemophilia Society has certainly made its fair share of mistakes, is the hardship fund going to be another Society blunder? We look forward to receiving your reply to our letter.

With Thanks

Yours sincerely

Carol Grayson and Peter Longstaff.

Cc. Press –various
MPs- various
Weber- Shandwick
Lord Morris Of Manchester