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Carol Grayson
Haemophilia Action UK
PO Box 782
Newcastle upon Tyne
NE2 2UW

Tel GRO-C
Email: kunming@ GRO-C

For the attention of the Chairman, the Chief Executive and ALL Trustees of the Haemophilia Society.

Dear Chris,

Thank-you for your letter of 19th July. We will reply on a number of points.

Firstly you mention the HCV postal questionnaire for members however you have not addressed our initial point that the questionnaire DID NOT ballot members on a "hardship fund" or give alternative options such as recompense on a parity with Eire.

You mentioned that the Society has made a sizeable investment from reserves to increase the campaigning activity with support from professional public affairs experts Weber Shandwick. Haemophilia Action UK is run by people with no sizeable resources, living on disability benefits yet despite this obvious handicap we seem to have managed a sizeable amount of media coverage on haemophilia issues, are moving forward on a number of campaign aims and have built up good credibility with the press. We hope you will take the time to listen to BBC Radio 4 (details will be e-mailed to you) and listen to the program we worked on to raise the profile of haemophilia issues. There are further documentaries in the pipeline.

We are under no illusion as to the difficulty of exposing the truth of the contamination issue and obtaining justice but we know that right is on our side and we will fight for as long as it takes.

You state that you have sought advice from legal, public affairs and medical experts, as we know from the history of our haemophilia community, experts from these specialist fields have not always been right in their opinions so we reserve judgement on that for the moment.

If the Society has not departed from seeking recompense then why is recompense not stated as a specific campaign aim so we all know where we stand. How can we support a campaign when the aims are confusing and are not made clear? Can you confirm or deny whether you are still fighting to achieve one of the initial aims stated in your 1995 HCV campaign information- a lump sum pay-out. Haemophiliacs would like this clarifying and so would the press. A widow friend of ours phoned the Society prior to the AGM to ask questions about the hardship fund and was told that it was quite likely a hardship fund would be means –tested. If this is not the case let's see this stated IN WRITING.

In your letter you write that the Macfarlane Trust was originally set up as a "hardship fund", we have been informed this week by a reliable source, Ann Hithersay, administrator of the Macfarlane Trust that at no time have the words "hardship fund" ever appeared anywhere in the deeds or written documentation of the trust so perhaps you need to re-think the information the Society is sending out!

We recall that up until fairly recently the Society was calling for an extension of the Macfarlane Trust for those infected with HCV, which we checked out at the time. Ann informed us some time ago that the extension of the trust had already been looked at in relation to the Eileen Trust but was in fact illegal. A separate trust for HCV would need to be set up, this would also get way from the myth spread around that the Macfarlane Trust deeds include HCV and that the needs of co-infected haemophiliacs are catered for with regard to hepatitis C, NOT TRUE! The Society does itself no favours by sending out information, which is factually incorrect!

You mention that Weber Shandwick were not given a proper opportunity to present the new campaign strategy, for many the AGM is the only opportunity infected haemophiliacs have to be seen and heard. We were also aware that one of the Weber Shandwick team mentioned during the presentation that she would be leaving before the end to catch a train. Haemophiliacs were very worried that Weber Shandwick would only have had (to use your own words) a "partial snapshot" of the contamination issue and the historical context. Weber Shandwick cannot do their job properly if they are relying totally on one perspective, that of the Haemophilia Society. Many haemophiliacs are no longer members of the Society having lost faith in the Society's campaign but they deserve justice for the damage caused.

Haemophiliacs want recognition of damage, it's not just about evidence of need and a hardship fund on its own is a total insult completely devaluing their lives. How do you define need anyway? You mentioned the 1996 report on the impact of HCV on the community, can you remind us was it this report or another which failed to interview one single co-infected member about the impact of HCV on their lives. Anyone who did not see co-infection as an issue at that time had obviously not considered articles such as Professor Christine Lees article in the BMJ VOL 310 24TH June 1995. "HEPATITIS C AND HAEMOPHILIA – Co-infection with HIV is common and will demand great resources," etc.

It is very hard to forget that for 5 years the Society was NOT campaigning for co-infected haemophiliacs as part of their campaign, we do keep all our letters and how could we possibly forget being told NOT to turn up for the Lilies campaign at Westminster in past years ("as it would be embarrassing if the Society had to remove us") the reason, Peter also had HIV as well as HCV. Our MP has certainly not forgotten that fact!

We note that "work is ongoing at the moment to develop specific proposals for a hardship fund for people infected with hepatitis C in this country." Please hear what infected haemophiliacs and their families are saying, WE DO NOT WANT A HARDSHIP FUND! We are very concerned that the national Haemophilia Society is damaging haemophiliac's fight for justice and a proper RECOMPENSE/COMPENSATION package.

We have taken issue with the Society on a number of occasions over the years, we certainly would not want to be misinterpreted as seeing the issue of a hardship fund as the only point on which we disagree, this is by no means just a monetary issue. One concern as we pointed out was the unprofessional attitude of trustees on more than one occasion, the latest being the incident with Mr Levvy. We feel it only fair to mention that we have raised various concerns with the "Charities Commission" and sought their advice. Haemophiliacs and their families await to hear Mr Levvy's version of events when he returns from holiday.

You also failed to respond to concerns over the double standards of a trustee supporting the Society's campaign for a hardship fund for haemophiliacs who are members yet approaching our solicitor on the back of our case who is fighting for justice and COMPENSATION/RECOMPENSE.

We don't require the 1991 minutes, we already have them, sent out to some members by a trustee in 1991. You state these only represent a partial "snapshot". What concerns me is that the Society took the stance that hepatitis C wasn't a big issue at a time when even the Government admit in writing that haemophiliacs had died from hepatitis C and others were seriously ill. This attitude continued for years until a campaign was finally launched in 1995. We campaigned for some time before this on our own without any support or information. The attitude of the Society and the accuracy of the information on HCV in 1991 was essential to haemophiliacs understanding of hepatitis C. Haemophiliacs were seeking advice on HCV in order to make an "informed choice" about signing a "waiver" in the HIV settlement. One of their main points of reference was the Society. Is it any wonder they all signed the waiver?

The information put out by the Society at that time was in total contrast to the medical evidence and many research papers that had been published on HCV. You have still failed to give members the names of the "experts" the trustees approached for opinions on HCV in 1991. We believe Simon Taylor was one of those trustees, surely he would remember who gave this advice! We are now at the stage of instructing expert witnesses for our case and would hope that our national Haemophilia Society that is supposed to represent the rights of members could at least provide us with information on these "experts." Are you going to force us to pursue this via legal channels?

We look forward to your response to this letter which will then be passed on to our MP. We will have to give careful consideration to the invitation to the briefing meeting on the 11th of September, unfortunately our experiences to date of our national Haemophilia Society have rarely been positive ones.

Thank-you for taking the time to read this.

Yours sincerely

Carol Grayson & Peter Longstaff
Haemophilia Action UK

cc Lord Morris
Weber Shandwick
MPs various
Press various