

04/08/2001

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Tel: GRO-C

Email: kunming GRO-C

FOR YOUR ATTENTION: - 'FACE THE FACTS'.

Dear Haemophilia Society Trustee,

You may have heard the "Face The Facts" program, BBC Radio 4, on 3rd August at 12.30, lunchtime. I am writing to inform you how this program came to be made.

You may or may not be aware that I have been working alongside a journalist on "Private Eye" providing information and contacts for several articles related to haemophilia. Out of that relationship came the Radio 4 opportunity. I received a phone call a few weeks ago from my "Private Eye" contact to say that there had been some discussion between "Private Eye" and "Face The Facts" journalists and that they wanted to give haemophiliacs a chance to have a voice.

Will Yates (a researcher) came to Newcastle and spent 7 hours with us looking at the history of contamination, collecting evidence and taping interviews. I gave him a list of reliable, well-informed individuals for interview (most of whom featured on the program). I suggested and gave contact details of Dr Mark Winter, Professor Preston, Lord Owen and Lord Morris in addition to haemophiliacs and their families.

I initially rang Lord Owen months ago and remain in touch by e-mail. He was very helpful asking me to write to him and send him information, which I did and out of that came Louella Houldcroft's excellent interview with him, which was recorded a while ago and published on the 2nd August to coincide with "Face The Facts". Up until we contacted Lord Owen he said he had not been approached for years on the subject of blood contamination and appeared surprised that some of us were still interested in what he had to say.

I mentioned my contact with Lord Owen to Chris (Hodgson) I believe it was at the Macfarlane Trust registrants' day for trustees where we gave presentations on what life is like living every day with deadly viruses. I also recall speaking to Chris some time after that and him talking about making contact with Lord Owen himself. I think he stated that he or his brother knew Lord Owen from School.

Our media contacts are aware of the issues of conflict between haemophilia campaign groups and the Society and that the Society is unlikely to put our names forward for interviews with the press therefore blocking our chance to voice the issues which concern us. It appears that the Society can only cope with haemophiliacs who are not so well -informed on haemophilia issues, "safe" members as we call them. Once haemophiliacs are empowered through education they are seen as a threat to the Society and "dropped" as contacts for the press. We are forced to make our own media alliances and it is quicker and often much more productive to just get on with the job ourselves. We seem to manage despite the fact that we don't have the resource of a PR company such as Weber Shandwick, we do what we can on disability benefit and a carer's allowance!

Although we disagree on a number of issues with the Society we were happy to put forward the name of Lord Alf Morris as a politician and forthright campaigner on

haemophilia issues to-day and indeed prior to him becoming President of the Society. Radio 4 did not feel it necessary to use the Society in the program although the Society was contacted for some basic stats/facts. I am informed that the Society was found to be "unhelpful" and no information from the Society was used for the program.

I felt the program gave a very good overview of the whole complicated contamination issue in a way in which the general public could understand. It is important to get public support and we are very grateful to be have been given that airtime.

The Society has failed infected haemophiliacs for years. It has not made important information available when needed, has been unsupportive on many occasions, failed to respond to press and failed repeatedly to listen to members giving us no option but to go our own way and make it known that the Haemophilia Society is no longer the voice for all haemophiliacs. We understand that the Welsh group was the last casualty to break away from the Society feeling much the same as we do! Can you confirm whether you have any representation at all in Wales now? We recognize however that the Society plays an important role in supporting the younger generation who thankfully are mostly virally free.

We find it very sad that articles such as Louella's piece highlighting Lord Owen's views do not appear to have been published at the time he first spoke out in 1988 about his concerns over "maladministration of funds" ear-marked for self-sufficiency. He wrote in support of contaminated haemophiliacs at that time. The failure of the Government to respond to his questions and his calls for an investigation should surely have been taken up by the Society more forcefully then.

He was making a strong stand aiding haemophiliacs in general by focusing on one of his constituents and I wonder what support Lord Owen got from the Society! Was the Society in fact in touch with him? Lord Owen spoke out from the early days on safety matters as highlighted in the 1975 World In Action documentary, that was his reason for fighting for self-sufficiency. He was aware of the dangers of importing plasma made from paid donors and the hepatitis risks. There is plenty of evidence to document this so why has he not been approached for so many years, he is still an important voice!

We also note that in the HCV campaign unlike haemophilia societies in some other countries there has been very little condemnation of the past dangerous and immoral practises of some of the international plasma companies. It is very distressing to access the Haemophilia Society website and find the names of some of our contaminators whizzing before our eyes! Do you have to advertise these companies? It is one of the first things on which infected members remark with regard to the new website. Companies have made enough profit from selling contaminated products, not only have they made profits from sale but they have sued blood brokers for supplying contaminated plasma for millions of dollars without giving a penny to those infected!

We are currently involved in helping researchers for a major new scientific documentary series on blood consisting of 4 x 1 hour slots which among other things will feature the contamination of haemophiliacs, we meet the director next week. It will be interesting to see how much the Haemophilia Society is consulted on this one, if at all!

Yours sincerely

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Carol Grayson (Haemophilia Action UK)