Roger Godsiff

HOUSE OF COMMONS
LONDON SW1A 0AA

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1st April 1999

Ms. Karin Pappenheim,
Chief Executive,
Haemophilia Society,
Chesterfield House,
385 Euston Road,
London, NW1 3AU.

Dear Karin,

Thank you for your letter of the 29th March. I am sorry that Ian and myself missed the meeting on the 17th March but I was already committed outside of the country on that day and Ian had a late opportunity of joining me which, understandably, he did not want to turn down.

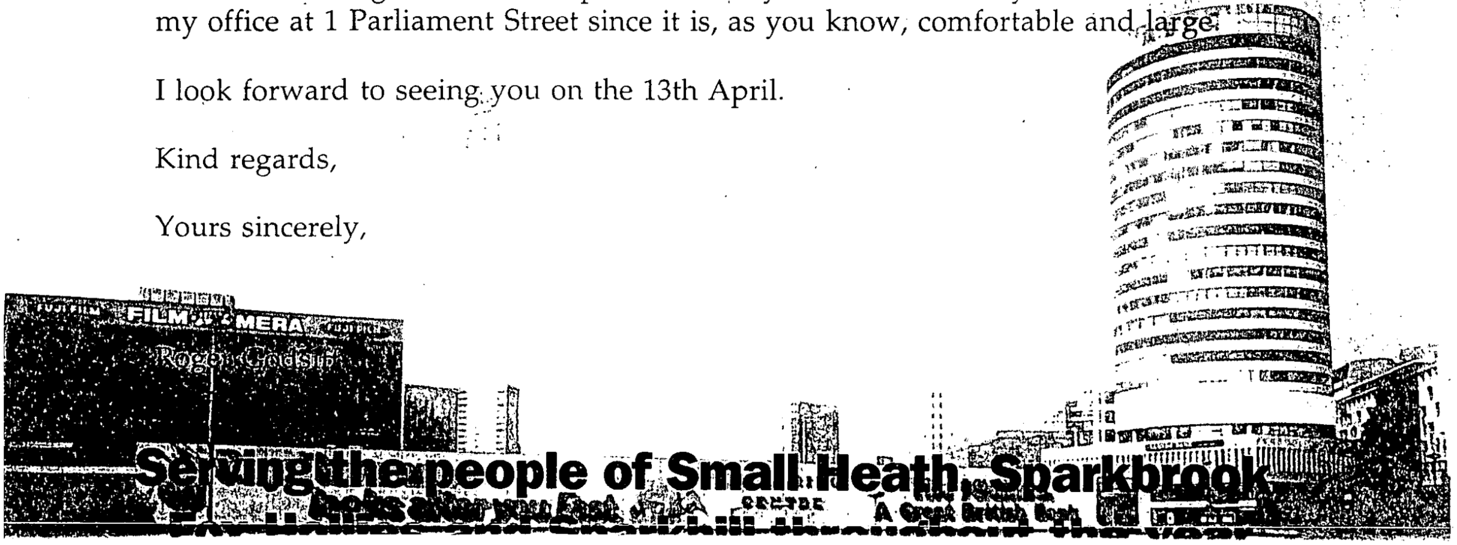
I have read the notes of the meeting and I am more than happy to give my full support to the on-going campaign to achieve justice for the small group of haemophiliacs who have been infected with the HIV virus. So far as I am concerned they have a cast iron case in terms of morality and I am happy to work with Alf Morris to try and get the Government to accept the justice of their case.

I had, incidentally, left a note for Ian to find out what was happening with the campaign. He was away on the week before the Easter Recess but he will get my note, together with a copy of your letter and my letter to you when he returns from the Easter holiday. I will ask him to contact Sue in your office to confirm that I will be at teh meeting on the 13th April and it may be convenient if you and Alf met in my office at 1 Parliament Street since it is, as you know, comfortable and large.

I look forward to seeing you on the 13th April.

Kind regards,

Yours sincerely,



THE HAEMOPHILIA SOCIETY
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Roger Godsiff MP
House of Commons
LONDON
SW1A OAA

KP/sr399/34

29 March 1999

Dear Roger

I'm sorry you and Ian missed the meeting on 17th March with MPs and peers about the HCV campaign, but understand you were abroad. Your note of support was received, however, and passed on to Lord Morris.

It was a good meeting, following which we are considering a number of actions. The two most high profile of these are (1) to organise debates in the Commons and Lords and (2) to arrange a cross-party delegation to the Prime Minister. Lord Morris has offered to facilitate the latter and we are hoping you will be a co-leader of the delegation with him. Clearly, it will be important to make the request for the meeting to Number 10 in such a way that it cannot be turned down easily, and we will need to plan carefully to ensure this.

I am coming over to Westminster to meet Lord Morris at 3.30 on Tuesday 13th April to discuss next steps. If you are free that afternoon maybe we could meet then. Could you or Ian contact Sue in my office to fix this (I'll be away myself from 31st March to 9th April).

In the meantime, here are some notes of the meeting on the 17th.

Best wishes

Yours sincerely

GRO-C

Karin Pappenheim
Chief Executive

All Party Parliamentary Meeting on Hepatitis C
17 March 1999

Speakers
Lord Alf Morris (Chair)
Chris Hodgson (Chairman, Haemophilia Society)
Karin Pappenheim (Chief Executive, Haemophilia Society)
Lucy McGrath (Hepatitis worker, Haemophilia Society)
GRO-A

Attendees
Win Griffiths
Mark Fisher
Lord Burlison
Baroness Masham of Ilton
Daffydd Wigley
Jim Cousins
Jim Dobbin
Bob Russell
Sir Geoffrey Johnson Smith
William Ross
Sir Peter Lloyd
Stan Cockburn (Chairman, Manor House Group)
Jan Hardy (Vice Chairman, Manor House Group)
Sue Rocks (PA to Chief Executive, Haemophilia Society)

Non Attendees
Alan Duncan
Alan Hurst
Andrew George
Brian Iddon
Gerald Howarth
Gerry Bermingham
John McAllion
Llin Golding
Malcolm Chisholm
Melanie Johnson
Mike Hancock
Norman Godman
Roger Berry
Terry Lewis
Melanie Johnson

Apologies
Roger Godsiff MP
Simon Taylor (Haemophilia Society)

Meeting Report

The meeting was chaired by Lord Alf Morris, who introduced the speakers and outlined the importance of the campaign for justice for people with haemophilia infected with hepatitis C. He explained that the meeting was being held to take the campaign forward and that the help and advice of all the MPs present was needed. He then handed over to Karin Pappenheim of the Haemophilia Society

Karin Pappenheim

Karin Pappenheim detailed information about the infection of the haemophilia community, activity to date in the campaign, and the next step.

Infection information:

- The haemophilia population is very small - only 6,000 people
- Almost every patient treated for haemophilia with clotting factor concentrates by the NHS before 1986 was infected with hepatitis C - some 4,800 people
- Of that 4,800, 1,200 were also infected with HIV
- Blood products were contaminated because there were no screening or viral inactivation processes available
- Blood products are now inactivated and no longer transmit hepatitis C, so the number of people with haemophilia and hepatitis C will not grow larger
- Hepatitis c attacks the liver. Up to 80% of those infected will develop chronic liver disease, which may progress to liver cirrhosis or cancer
- Progress of the virus can take 20 - 30 years
- There is no fully effective treatment. Interferon is the only licensed treatment in the UK and its success rates are low for those with haemophilia
- Hepatitis C infection, like HIV carries heavy stigma
- Those infected cannot obtain life insurance or mortgages
- Those infected have suffered loss of earnings through ill-health

Campaign information:

- In 1989 the Society persuaded John Major's Government to establish a hardship fund for people with haemophilia infected with HIV
- In 1998 the Society persuaded Frank Dobson to make synthetic clotting factor available to children under 16 with haemophilia
- There has been a constant stream of Parliamentary Questions
- An EDM is in place
- There was a Lords Debate in June 1998
- There was a lobby of Parliament in 1998
- There was a petition to the Prime Minister in July 1998
- A cross party lobby led by Roger Godsiff spoke to Baroness Jay in June 1998
- Just before the summer recess in 1998 Frank Dobson turned down the Haemophilia Society appeal for financial help

Next step

The campaign is not just calling for financial assistance, it is also about truth and social recognition. A public enquiry is needed to investigate how and why the contaminated blood products came to be used, whether enough was done at the time to prevent the infection of patients and what the full impact has been on those infected.

Other countries have had or are holding inquiries. Canada and Ireland are two cases in point. The Society has written to David Hinchliffe of the Health Select Committee and Frank Dobson to request that an inquiry is held.

The next speaker was Lucy McGrath, Haemophilia Society Hepatitis worker. She outlined the international situation.

International Situation

Canada
An inquiry has been held in Canada and found that their blood system was at fault and compensation is available in varying degrees to those infected.

Ireland
A compensation Tribunal is operating to investigate and recommend levels of compensation for those infected.

An inquiry into the HIV and hepatitis C infection of the haemophilia population has recently been established.

Full information can be found in the pack enclosed with these minutes.

The next speaker was GRO-A

GRO-A
GRO-A is 24 years old and has the bleeding disorder von Willebrand's disease. She detailed her experiences of living with hepatitis C. She said that she had lost her job as a result of the virus and was suffering hardship, both financial and physical.

The next speaker was Chris Hodgson, Chairman of the Haemophilia Society.

Chris Hodgson
He recapped on what had been said previously and added that, like most of the haemophilia population of his generation, he had hepatitis C. Every member of the Society's Trustee Board is affected by hepatitis C or HIV or both.

Alf Morris then threw open the meeting to discussion.

Questions raised by MPs were:

Are people taking a legal course of action?
The answer was that there are a number of people taking individual legal cases against their health authorities where it can be shown they were treated inappropriately and that the treatment could be seen as negligent.

Is there any possibility of a class action as happened with HIV?
The legal situation is not comparable to that which arose with regard to HIV when Government faced approximately 900 court actions on behalf of individuals. There are a number of HCV cases being taken forward, but they are still some time from getting to court. These include people who were infected through blood transfusion as well as people with haemophilia infected through

contaminated blood products. The actions are either against individual health authorities or the National Blood Authority (NBA). A major difficulty is that the cost of the actions is prohibitive and that people with haemophilia and hepatitis C are already experiencing financial hardship. The Society is not pursuing court action as the means to resolve this issue.

What about people who were treated around 1986 taking individual actions, as they are more likely to be successful as it would be harder to defend the proposition that they received the best possible treatment at the time?
There are a number of cases ongoing, but that they are still some time away from reaching court. The view of the Haemophilia Society has always been that the better approach is to put pressure on the Government to make ex gratia payments. This is how the Society obtained a hardship fund for those infected with HIV.

What did the Government say about the fact that they had a moral responsibility for the infection of the haemophilia population?
They avoided the issue and continued to say that the best treatment available was used.

Do you think that the reason the Government is delaying is because they feel that there are large numbers of people over and above those with haemophilia infected with hepatitis C and that they may need to pay out large sums of money?
We've had indication in answers to questions that the Government's thinking would be that it would cost them £220 million. However, we don't know what they are basing their figures on. This is a good argument for the public inquiry into the whole blood products issue so that we can obtain firm figures of how many are infected, how many have died, what the state of health of those infected is, how the blood and blood products supply became infected, what could have been done to minimise the effects of that infection and many more questions.

There is also the issue of those co-infected with HIV and hepatitis C. The literature from the Society says that they are included in the campaign.
That's true. The co-infected have to face the effects of HIV and hepatitis C at the same time.

We heard from one speaker the financial difficulties she experienced before she finally received her benefits and the problems that debt are still causing her. We must try to ensure that benefits are simplified as at the moment they are too complicated for ordinary people to complete.
All present agreed.

Lord Morris then thanked everyone for attending .

Karin Pappenheim also thanked everyone and said that the Society will be in touch with all those attending as well as those who had been unable to attend to let them know ways in which we would like them to help.