THE HAEMOPHILIA SOCIETY
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Patron: HRH The Duchess of Kent
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Report to Campaign Group from Karin Pappenheim

MPs Meeting with Baroness Jay, 15 July 1998

This morning, as you know, Baroness Jay, the junior Health Minister, met with Roger Godsiff and an all party group of our supporting MPs. Those attending were: Stephen Hesford (Wirral West, Lab); Geoffrey Johnson Smith (Wealden, Cons); Dr Peter Brand (Isle of Wight, Lib Dem); Paul Goggins (Wythenshaw and Sale East, Lab); Bill Etherington (Sunderland North, Lab); Dafydd Wigley (Caernarfon, PC); Paddy Tipping (Sherwood, Lab). I attended as an observer.

The MPs presented our case very powerfully, drawing on their own constituents' experiences and our briefing to them. (See attached).

In general it was a very positive meeting, which helped tease out what the sticking points are for Government and how we can push forward our case. Baroness Jay was very well briefed on the issues. As you know she is former director of the National Aids Trust, and in that role had been involved in establishment of the Macfarlane Trust.

She made two central points:

1) Why should people with haemophilia with hepatitis C infection be treated differently from others who have received HCV infection through their NHS treatment i.e. via blood transfusions or tissue transplant?
She indicated that it would be hard for Government to provide financial assistance for our group and not for the others who are also HCV infected through NHS treatment. She also alluded to the 'long list' of other patient groups who have problems resulting from the NHS treatment (e.g. those treated with cortico steroids, those unhappy with their treatment for breast cancer). It was forcefully argued by our supporting MPs that people with haemophilia are a distinct case, and that Government has already established a precedent for them by giving financial assistance to those with HIV infection. Clearly Government is very concerned about opening the way to further claims if they provide financial assistance to people with haemophilia who are HCV infected. However, as was said at the meeting, that should not be a reason for avoiding their moral responsibility to people with haemophilia and HCV.

2) What are the medical facts about HCV, the progress of the infection and how could you determine eligibility for financial assistance as the Macfarlane Trust does?
Here she seemed to be looking for answers from us, and seeking proposals for an assessment framework of the kind Mac Trust operates. It was useful to have Dr Brand there, as a medical practitioner he was able to provide information about HCV and haemophilia treatment, and I had an opportunity to explain the facts with regard to medical prognosis, and treatment prospects for HCV infected people with haemophilia.

The other key issue raised during the meeting was the conclusion of the Comprehensive Spending Review, which we now know has provided an extra £21 billion for Health, and should offer Frank Dobson more scope to act. Within that £21 billion it was suggested there must be some funding available for our HCV group.

Outcomes:

The Baroness spent an hour in discussion with us, which indicates Government is still very actively considering the options, and we were able to find out much more about why Government regards the issues as 'complex' i.e. what they see as the barriers to action. In summing up it was stressed that the most practical way of providing help without setting a new precedent would be to extend the terms of reference of the Macfarlane Trust to cover HCV, and we believe Baroness Jay will now be looking very seriously at that option.

Follow up actions:

Roger Godsiff is writing back to Baroness Jay thanking her and re-stating the key points in our case made during the meeting. I will write back to her also and offer further clarification on the questions she raised.

Karin Pappenheim
15 July 1998

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Briefing for MPs attending meeting with Baroness Jay, 15 July 1998

Key points

Who is the campaign for?

The haemophilia community is a small patient group (6,000 national total) who have suffered one of the worst medical disasters in the history of the NHS. Prior to 1986 almost the whole of that small population were infected with HIV, hepatitis C (HCV) or a combination of both through their NHS treatment with contaminated blood products. Since 1986 viral inactivation procedures have been in place to prevent such infection through blood products.

Latest figures indicate 4,800 were infected prior to 1986 with HCV, and 1200 with HIV. It is now known that virtually all of those with HIV were coinfected with HCV; today only 498 of that HIV/HCV coinfected group are still alive, half the original total having died. **Some 3,600 individuals are estimated to be infected with HCV alone. 90 haemophiliacs are estimated to have died as a result of HCV infection.**

The focus of this campaign is those 3,600 people who are mono-infected with HCV. Unlike those with HIV, they have received no financial assistance from Government although they were infected in exactly the same way through their NHS treatment and are suffering with an equally deadly virus.

What do we want?

The previous Government under John Major recognised it had a moral responsibility for people with haemophilia infected with HIV through their NHS treatment, and in 1989 provided funding to establish the Macfarlane Trust, which has since given out hardship grants and ex gratia payments totalling over £80 million. Another top up of £3 million was added at the end of last year.

But no such help has been offered to those with HCV. We want to see an extension of the principle of moral responsibility to those with HCV and financial assistance made available through a separate fund to offset their hardship and suffering. This could be set up on parallel lines to the Macfarlane Trust, drawing on their experience of administering funding in this area.

Politicians of all parties support this argument, and view it not as a matter of Right and Left but of right and wrong. They cannot see a distinction between the needs of those with HCV and HIV, and regard this as a moral issue and an injustice which this Government must put right.

Key questions we would like to ask

1) **The Government has said the issues are 'complex'. What does Baroness Jay see as the complicating factors?** (Is it the numbers involved; the potential claims of other HCV infected people i.e. through blood transfusions or tissue transplants; the risk of CJD claims in the future etc)

2) **Has Government considered setting up a hardship fund to provide grants on the basis of need like Mac Trust for HCV people with haemophilia and what do they feel there are practical barriers to implementing this?** (are there practical problems about determining

eligibility for a grant? do they have an estimate of how many individuals might be eligible on basis of need?)

3) **Is the Government aware of how much suffering the delay is causing in the haemophilia community?** Those infected with HCV feel abandonned, frustrated and very angry - the mental health of many is suffering as a result.

4) **Is the imminent completion of the Comprehensive Spending Review going to allow the Government to provide a positive response?**

5) **Is the Baroness aware of the lobby next week (22 July) by patients with haemophila with presentation of the petition to the Prime Minister? Will they be able to respond before that date?**

6) **How does the Government justify offering help to people with HIV infection and none to those with HCV when they were infected in the same way and are suffering an equally life threatening virus?**

Possible arguements from Government against offering financial assistance

1) Providing financial assistance will take money away from patient care and from Government priorities in terms of hospital waiting lists
Not so: the HIV settlement came from contingency monies, this could be done again for HCV. This is a small and very vulnerable patient group: Government has stated its commitment to vulnerable groups in our society, and people with haemophilia and HCV infection are surely that. Government has also stated its determination to rebuild public confidence in the NHS: one way of doing that would be by providing justice for for people with haemophilia who have suffered as a result of their NHS care.

2) HIV was a totally special case; HCV is different
Not so. Baroness Ramsay (Lords debate 5 June) argued that Government had given special help to HIV infected haemophiliacs because they were a very special case a) because of public stigma and revulsion b) because of fears of transmission within the family. Our members with HCV can testify that stigma attaching to HCV is great: some have lost friends or had to leave jobs because of it, and report hostility from neighbours. Assumptions are made about those with HCV ie. that they are all drug abusers and/or sexually promiscuous. As for transmission, all our members report extreme anxiety about transmission within families from parent to child and from partner to partner which place a great strain on family life. We have instances of such transmission as well.
It should be acknowledged also that in 1989 treatment prospects for HIV were very much worse than they are now with advances in combination therapy, while today treatment prospects for HCV are very poor. It could be strongly argued that prospects for haemophiliacs infected with HCV are as poor as those with HIV infection were nine years ago when Government first decided financial assistance should be provided for the HIV infected group.

3) Giving help to HCV infected haemophiliacs will open the floodgates to other claims
This should not be so. We acknowledge that there other groups, such as those infected via blood transfusions, but this should not prevent the Government acting for people with haemophilia who represent a very special case on moral grounds. This is a small patient group, already vulnerable

due to their lifelong, often disabling condition, and there can be few other communities which have suffered so devastating an impact given that almost all treated prior to 1986 are believed to have been infected. However, we know that the HCV infection has been contained since 1986 by viral inactivation procedures, hence it is not an expanding group. If the Government has accepted the moral principle for those with HIV infection how can it not accept the same responsibility for those infected with HCV in the same circumstances.

4) People with haemophilia were given the 'best treatment at the time'
Whether that is so or not, the fact remains that the majority of haemophilla patients contracted either HIV or HCV infection via their NHS treatment during the 70s and 80s. One of the reasons for their anger is that the risks of this infection via treatment with blood products were not explained to them as patients, and those with mild haemophilia in particular feel that if the risks had been explained they would have declined treatment other than in extreme urgency. Undoubtedly this group have suffered more as a result of their HCV infection than they would have through their haemophilia. Whether or not it was the best treatment at the time should not detract from the moral responsibility which must be as great with respect to those infected with HCV as it is for those who are HIV infected.

Karin Pappenheim, Chief Executive
Haemophilia Society July 1998