John Randall, MP

HOUSE OF COMMONS
LONDON SW1A 0AA

19 July 2007

Dear Dawn

Thank you very much for your letter of 10 July 2007, reference PO 00000216891 regarding haemophilia patients infected with contaminated blood products following NHS treatment and I am grateful for the information that letter contained.

However, I have again heard from the Haemophilia Society and I enclose herewith a copy of the correspondence I have received from Mr. Chris James, the Chief Executive. I would very much appreciate your comments on the points he has raised.

I look forward to hearing from you.

Yours ever

GRO-C

Rt. Hon. Dawn Primarolo
Minister of State
Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

Caring for people with bleeding disorders

THE
HAEMOPHILIA
SOCIETY
UNITED KINGDOM

Petersham House
57a Hatton Garden
London EC1N 8JG
Helpline: 0800 018 6068
Admin: 020 7831 1020
Fax: 020 7405 4824
Email: info@haemophilia.org.uk
Website: www.haemophilia.org.uk

John Randall MP
House of Commons
Westminster
London
SW1A 0AA

16th July 2007

Our Ref: AS/RM/Randall

Dear Mr Randall,

Thank you very much for your letter to our Chairman, Roddy Morrison, dated 12th July, which enclosed a response from the Minister for Public Health dated 10th July. We are very grateful for the time that you have taken to contact the Minister to raise your concerns about the contaminated blood disaster.

The Minister's response is a standard one, essentially repeating the line that the Government has held for over two decades. Unfortunately, this response raises more questions than it answers.

Please could you write back to the Minister to ask the following questions?

1. Why she is certain that the contaminated blood disaster could not have been prevented when no investigation has been carried out into its cause?
2. How can the 4,670 people infected with deadly viruses be confident that lessons have been learned when there has been no Government-backed inquiry to discover whether swifter action could have been taken to secure the safety of the blood supply?
3. Why has the Government only reviewed documents relating to non-A non-B hepatitis between the periods 1970-1985? This limited remit excludes HIV (which was the topic of the bulk of the documents) and does not explore the crucial period of 1985 to 1991.

I enclose a briefing which explains that the Government missed several opportunities to improve the safety of the blood supply. The haemophilia community is concerned that, unless there is a full, official public inquiry, the lessons of these past failures will not be learned.

The Haemophilia Society is very appreciative of your continued support, and hopes that you will be able to elicit an answer to the above questions from Dawn Primarolo MP.

We look forward to hearing from you.

Yours sincerely,

GRO-C

Chris James
Chief Executive – Haemophilia Society

Summary of the Haemophilia Society's Submission to the Archer Independent Public Inquiry into Contaminated Blood

What is Haemophilia?

Haemophilia is a hereditary condition characterised by low levels of clotting factor in the blood. People with mild haemophilia have some clotting factor and are less badly affected than those with severe haemophilia who have virtually no clotting factor. There was no effective treatment until cryoprecipitate was discovered in the 1960s. The introduction of freeze-dried, plasma-derived factor concentrate in the 1970s transformed the lives of people with severe haemophilia, allowing them to be active and treat themselves at home. Unfortunately, these products, which were made from untreated human blood, were contaminated with deadly viruses such as HIV and hepatitis C.

Contaminated Treatment

4670 people with haemophilia were infected with HIV and/or hepatitis C through contaminated blood products in the 1970s and early 1980s. That represents four out of every five people living with haemophilia at the time. HIV attacks and infects cells in the body which are part of the immune system, while hepatitis C attacks the liver and can lead to cirrhosis and liver cancer. As a result, 1,757 people who were infected have since died, and many more are terminally ill.

An Independent Public Inquiry into the circumstances surrounding the supply of these contaminated blood products to patients is currently underway.

The Haemophilia Society believes that many of these infections were preventable, and has presented evidence which shows a catalogue of mistakes and delays by both the Government and the NHS.

We have identified seven specific failures:

1. The failure to pursue self sufficiency in blood products. Despite having a policy of self sufficiency, the UK continued to rely on commercial blood products imported from the USA. Many of these were made from the blood of paid donors, including prisoners and people living on 'Skid Row'.
2. The failure to introduce a surrogate test for 'non A, non B' hepatitis (now known as hepatitis C) when most other developed countries used this test. This would have prevented the use of blood from people with abnormally high liver enzyme levels.
3. The failure to restrict the use of clotting factor in less urgent cases once the risks of HIV and hepatitis C infection became known. Rather than being a life-saving treatment, clotting factor was continued to be used as a precaution to prevent bleeds occurring, and to treat people with mild haemophilia.
4. Delays in introducing HIV screening, both of blood products and donors. The first test was developed in 1983, but screening was not introduced until late 1985.
5. Delays in introducing the heat treatment of blood products. This should have been introduced in 1983, but only became available in the UK in 1985. Heat treatment of blood products at a temperature high enough to kill hepatitis C only commenced in Scotland in 1987.
6. Delays in informing patients of their viruses, leading to the infection of partners.
7. Delays in introducing hepatitis C screening. A test for hepatitis C was developed in 1989, but not introduced in the UK until 1991.

We have therefore found that the contaminated blood disaster was largely preventable, and are determined that the Government must learn from the mistakes of the past in order to prevent a disaster like this recurring in the future.

The Effect of the Infections

1,727 people infected with deadly viruses have since died. Many more are chronically or terminally ill. Because haemophilia is a genetic condition, many families have suffered multiple bereavements, which adds to the feeling to devastation.

The Archer Inquiry has heard personal testimonies of the enormous stigma that people with HIV and hepatitis C have had to endure as a result of their infections. As recently as 2004, assistance had to be given to help a man to move home to escape persecution. The stigma of HIV and hepatitis C means that carers and bereaved relatives often feel that they have no-one to turn to for moral or practical support. There is also the worry of household transmission, and there are 63 known cases of partners becoming infected with HIV.

The threat of passing on the HIV and hepatitis C viruses to partners and unborn children is a considerable barrier to starting a family, and the birth rate in the haemophilia community has halved since the early 80s.

The financial consequences of the viruses on infected families have also been devastating. A fifth of people with hepatitis C and two thirds of people with HIV and hepatitis C are unable to work due to their illness. For those that are able to continue working, many have to reduce their hours of work, give up opportunities for promotion, or take a less demanding job. Discrimination and the attitudes of employers also present a barrier to returning to work. Access to insurance and other financial products is severely restricted for those with HIV and/or hepatitis C.

Lessons not Learned

In recent years many people with haemophilia received letters informing them that they had received treatment made from the plasma of people who subsequently developed vCJD. In addition, haemophilia centres wrote to patients in 2004 to inform them of a universal 'at risk' status if they had been treated with British-source plasma concentrate between 1980 and 2001. This caused anger as well as concern, because it took over a decade of campaigning for people with haemophilia to gain access to synthetic clotting factor, which is a much safer than blood products but more expensive.

People with haemophilia therefore feel that the lessons of the contaminated blood disaster have not been learned. This impression has been heightened by the lack of Government co-operation with the Archer Inquiry, and the fact that thousands of documents relating to blood products in the 1970s and 80s have either been destroyed, or are yet to be released.

This is a brief summary of the Haemophilia Society's submission to the Archer Inquiry. If you have any questions, or would like a copy of the full submission, please do not hesitate to contact GRO-A **, Communications Manager, on** GRO-A GRO-A