Freedom to make choices and seize opportunities for people affected by bleeding disorders

THE
HAEMOPHILIA
SOCIETY

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The Rt Hon Jeremy Hunt MP
Secretary of State for Health
Department of Health
Richmond House
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15th October 2012

Dear Minister

On behalf of the Haemophilia Society may I wish you every success in your new role.

The NHS commits significant resources to the treatment and care for bleeding disorders and we are grateful for the high standards of care across much of the UK. However, treatment is not uniform across the country and particular aspects require significant improvement, particularly access to provision of associated services including dentistry, physiotherapy, and psychological support.

We wish to see the care and treatment of people affected by bleeding disorders properly managed in the NHS Reforms, so that the strengths of the current system are maintained while structures for comprehensive treatment are improved. In addition, as any interruption to treatment for those with bleeding disorders can create long-term damage to patients (and considerable additional long-term costs to the NHS and benefits system); we are concerned that a period of reform could create such interruptions. It is vital that the National Commissioning Board and the supporting commissioning structure can deliver high-quality treatment and care across the UK including a robust National Service Specification for bleeding disorders and effective auditing of treatment.

The Society has a major role to play in promoting positive messages to patients including the need to adhere to treatment regimens and completing treatment records accurately. We know that this is vital in the measurement of patient outcomes which may lead to improvements in care and to the development of new treatments. There are significant treatment developments in the pipeline and our hope is that we can work together with Government in ensuring the introduction of these innovative products when available.

I know that you will be aware from your constituent Mike Dorricott of the devastating impact of contaminated NHS blood and blood products from the 1970s and 1980s and of the recommendations of Lord Archer's Independent Inquiry. I would be grateful if you would read our attached Policy which gives more detail on this and on the issues outstanding.

I would like to raise two specific issues directly with you. Firstly, as a response to the Archer Inquiry, the Department of Health established twice-yearly meetings with the Haemophilia Alliance, a group which includes the Haemophilia Society and patients; this allows an effective process for monitoring delivery of care and treatment and implementing corrective action as needed. We are grateful for the constructive nature of this relationship. However, we need a clear understanding of where responsibility for care of people with bleeding disorders will lie between Ministers, the DH and the

NHS Commissioning Board so that we can ensure effective patient representation and performance monitoring. We would like government assurance that, in the event that powers transferring from the DH to the NHS or to Commissioners, this meeting and its terms of reference will be expanded to involve the appropriate decision makers.

Secondly, at our meeting with the DH on 28th May we raised a number of issues relating to the on-going financial and social care needs of those people affected by contaminated blood. The Department officials informed us that these matters were outside the Terms of Reference of the meeting. The government accepted the first of the Archer recommendations, which called for a committee to cover "all provisions necessary to address the financial and other needs of haemophilia patients" [Archer Report recommendation 1 a) iii)]. Our meeting with the DH covers this for issues directly related to health, but we would like to know from you in what forum are we able to raise issues financial and social issues with government, as these are also vital to the health and well-being of a significant part of our community.

Again as a result of Archer, the government gives the Society a Capacity Building grant to help support the thousands of people affected by the disaster. This grant comes to an end in 2013-14 and we would like the opportunity to discuss with you its continuation beyond 2014 so that the Society can continue its work in this area.

Apart from direct health issues, we are concerned that proposed changes to the benefits system will have a detrimental impact on people with bleeding disorders, including those living with viruses. We have particular concerns over the replacement of Disability Living Allowance (DLA) with Personal Independence Payment (PIP) and the Work Capability Assessment. We would urge you as the Minister for Health to encourage "joined-up working" between the Department of Health and Department for Social Work and Pensions to ensure that patient care is not adversely affected by these changes.

We look forward to working with you and the Department, and we would welcome the opportunity to meet with you at the earliest opportunity to discuss the issues raised in this letter. I look forward to hearing from you with a suggested date for a meeting.

Yours sincerely,

GRO-C

Chris James
Chief Executive

The Haemophilia Society Policy on Contaminated Blood **September 2012**

Introduction

In the 1970s and 1980s, a large proportion of blood products supplied to patients by the NHS were contaminated with HIV or Hepatitis C viruses; at least 1,757[1] patients with Haemophilia have subsequently died from the effects of these viruses of the over 4,670 exposed to infection.

The risk of viral contamination, particularly from blood sourced in the USA, became known in the 1970s, although the existence of HIV and the lethality of Hepatitis C were not established until the 1980s. In response to the known risk, the Government in 1975 committed to the UK becoming self-sufficient in the main blood product used to treat Haemophilia (Factor VIII) 'within two to three years'. This promise was never kept. Heat treatment of blood products to destroy viruses finally became available in the early 1980s but was not fully implemented until 1986.

The NHS made no clear communication of the known risks to patients, and did not change practice to avoid use of blood products for patients who required treatment only infrequently and could have been adequately treated with safer alternatives.

Successive Governments have refused to hold a UK-wide Statutory Public Inquiry into these events. An Independent Inquiry under Lord Archer opened in 2007 and reported in 2009; this followed the procedures of a Statutory Public Inquiry but had no power to compel anyone to give evidence or to produce documents. Lord Archer made strong recommendations to Government, some but not all of which have been implemented. We recognise that there is an on-going Statutory Public Inquiry under Lord Penrose in Scotland.

Summary

This policy comprises three main requirements: an acknowledgement by the Prime Minister, a UK-wide Statutory Public Inquiry, and immediate interim steps to give equitable support to those affected.

This policy relates only to the Society's constituency of those with bleeding disorders. The Society recognises that people without bleeding disorders were also infected through whole blood transfusions, but it cannot express an opinion on the appropriate policy for this group.

The Society will review this policy after the Penrose Inquiry in Scotland reports in 2013.

Acknowledgement by the Prime Minister

The Society requires a public acknowledgement by the Government, given by the Prime Minister in a statement to Parliament, of the circumstances in the 1970s and 1980s which resulted in thousands of people being infected through contaminated blood. This should include recognition that mistakes were made by the Government of the time and by its Departments and Agencies, together with acceptance that this at the least creates the moral obligation on the Government to institute a payment and treatment regime for those affected which allows them to live in dignity and removes them from needing to rely on the benefits system or on a system of discretionary trusts. (They should of course still be able to access the benefits system if needed, as for the general population.)

Statutory Public Inquiry

The Society further requires a Statutory Public Inquiry into the circumstances which resulted in the contamination. The Inquiry terms of reference should include a focus on avoiding future medical disasters. Successive Governments have stated that they have learned and implemented all lessons from these events, but only a public review of the facts can prove this.

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[1] The numbers of deaths and infected are the official numbers recorded at 2007 quoted in the Archer Inquiry Report. It is likely that there were additional deaths from infection which were not recorded as such.

The Government must not, however, use the creation of such an Inquiry as an excuse for delaying rectification of current inadequate support for those affected, as outlined below.

<u>Equitable support</u>

Those infected often have conditions which prevent them working and which generate specialised medical needs. Both the infected and their families can have deep rooted psychological problems from the continued trauma of the experience; again this can require specialised treatment. Some partners have been infected through sexual transmission, and this has also led to some children being born with the infection, and these have the same needs as those infected directly. Where family members have acted as carers for decades with minimum support, this generates additional stresses and needs.

Given the immediate financial, medical, psychological, and counselling needs of many of those infected plus their dependants and survivors, the Society urgently requests that, pending any finding of fact and recommendations, Government implements an individual holistic needs-based and impact-based assessment for all those affected, with the goal of optimising clinical support, providing to the greatest extent possible for their emotional well being, and removing them from having to apply for further relief through the benefits system.

We believe that it is practical and affordable to run such a system for the few thousand cases which exist. If the Government queries the practicality of such individual assessment, we would suggest a trial to be run in a representative region of the country.

Pending the introduction of individual need-based and impact-based assessment the Society requires that the Government urgently rectifies gross inequities in the existing system, including:

- The process of applications by widows and dependants to the Skipton Fund, especially where medical records are missing. Where records are missing or inadequate, the "balance of probability" should be applied to make the assumption that an unexplained death of someone infected with Hepatitis C was caused by the virus's action on the liver and therefore qualifies for "Stage 2" payments.
- Medical evidence suggests that those individuals chronically infected with Hepatitis C, but with no visible damage to the liver, can still have chronic symptoms affecting their ability to earn a living and their need for support. The Skipton evaluation and payment regime should reflect this need.
- Recognition that those infected in general cannot get life assurance at any practical price and either (i) implement a Government underwriting scheme to provide affordable assurance or (ii) provide continued payments to the dependants after death of the infected person as a substitute for assurance. The scheme implemented should also resolve the issue of mortgages below.
- A similar problem exists, although to a lesser degree, for mortgages. Where those infected cannot get mortgages because the lender will not recognise the security of income and/or demands life assurance, the Government should provide confirmation of income and/or a scheme of assurance or the equivalent as above.
- Many carers of those infected have given up their own earning capacity over years or decades and are now themselves in serious financial difficulty. The Government should provide independent support to such carers on a similar basis to that on which it supports those infected.
- Dependants and widows of "first" families where an infected person has remarried are currently excluded from the payment scheme. Where appropriate they should be included.
- Psychological and long-term counselling support should be provided as needed for infected persons and their families. Given the sensitive circumstances for individuals needing such support, the channel of application should be designed to be sympathetic to their psychological needs and dignity.
- There are discrepancies between the payment regimes of the Caxton Foundation and the Macfarlane Trust; these should be levelled up so that the basis of payment is closely comparable.
- Those affected can spend excessive time accessing urgent medical care. The NHS should provide a 'Platinum Card' to those affected and provide training to ambulance and Accident & Emergency staff to recognise the card and provide care accordingly.