

Statement by the Board of Trustees of the Haemophilia Society on Contaminated Blood

Failures in government policy and negligence of public bodies led to people being infected with blood borne viruses as a result of their treatment with blood products in the 70s and 80s.

The impact of these failures was worsened by poor communication from Government, healthcare professionals, pharmaceuticals companies and The Haemophilia Society. Warnings were not heeded and errors were subsequently hidden.

Pharmaceutical companies and clinicians did not share, or even hid, information about risks from patients and patient groups.

Blood products, for the treatment of bleeding disorders, were made from pooled human plasma which was known to allow the transfer of viruses. Blood donations, particularly in the USA, were taken from high risk paid donors, often in prisons and without adequate processes to screen potential donors.

We condemn the actions and inactions of all parties that contributed to dangerous products not being withdrawn, patients not being properly informed of risks and technological and procedural advances ignored.

Support for those affected

Starting in the late 80s the Government has funded support for people affected by contaminated blood. Over time more people have been able to access this support and additional funding has been provided. However, this support has never been sufficient to alleviate the need of people with bleeding disorders and their families.

The additional funding announced last year to more than double the budget for contaminated blood support has not gone to those most in need and will ultimately leave many people with less support.

Other affected groups such as bereaved parents, partners and other family members have been particularly under-supported and ignored.

We do not think the current settlement is sufficient to provide the support people need and deserve. It does not allow them to have a reasonable standard of living rather than just be removed from poverty.

We reject the current proposals for reform of the support arrangements in England as they do not recognise the full needs of the bleeding disorder community, were poorly conceived and consulted on, do not provide sufficient support to people covered by the scheme and still exclude some individuals entirely.

For all people affected by bleeding disorders

The Haemophilia Society's position is that as a minimum primary beneficiaries should receive non-discretionary support at a level equivalent to the new scheme introduced in Scotland and have certainty that this level of support will be maintained for life. Bereaved partners and other family members also need long-term certainty and security of their support and at least in line with the levels proposed in Scotland.

A need for truth and justice

We want a full public inquiry under the inquiries act as only this could compel witnesses and would shed light on concerns such as:

- the inappropriate use of known infected treatments on previously untreated patients
- why and how British self-sufficiency in blood products was never achieved
- why tests to identify infected blood donations were not implemented sooner
- when and to what extent the UKHCDO, The Haemophilia Society, the Department of Health and the NHS held and were aware of information on risks and tests for infection with blood borne viruses
- why potential methods to heat treat blood products were not fully investigated and implemented sooner

To facilitate this we want a full and open disclosure of all information held by the Government, or elsewhere, relating to the sourcing, manufacture, procurement, licensing and NHS treatment with contaminated blood and blood products.

However, an inquiry must not distract from or delay the implementation of an improved support scheme.

The special case of people with a Bleeding Disorder

In recognition of the fact that the circumstances and reasons for their infection were different to people who were infected via a blood transfusion it is both appropriate and necessary that they and their families are treated differently.

The Government has previously accepted that people infected via blood products 'were an exceptional and specific group who merited exceptional treatment'¹.

For this reason there should be a separate scheme that administers support and compensation to people treated with contaminated blood products. The level and type of support required is likely to be different based on the psychological as well as medical impact of their infection and its circumstances.

The impact of the Contaminated Blood Scandal on the bleeding disorder community is vast and unique.

¹ <http://hansard.millbanksystems.com/commons/1991/dec/20/infected-blood-transfusions>

For all people affected by bleeding disorders

The Macfarlane Trust

The Macfarlane Trust was set up in 1988 as a charitable trust and provided with a grant from the Government to achieve its objective to 'relieve those persons suffering from haemophilia who as a result of receiving infected blood products in the United Kingdom are suffering from AIDS or are infected with HIV and who are in need of assistance or the needy spouses, parents, children and other dependents of such persons and the needy spouses, parents, children or other dependants of such persons who have died.'

The trust deed constituting the Macfarlane Trust (MfT) does not grant the Government, The Haemophilia Society or the MfT trustees the power to either amend the objectives or to cause the trust to cease to be a charity. Therefore the Macfarlane trust cannot be wound up by the Government and its beneficiaries and payments transferred to a new scheme administrator.

There are mixed views on the proposed move to a new scheme administrators but beneficiaries have a legal and moral right to continuing support from the MfT.

Legal Liability

Litigants in a 1991 legal case in the UK were not informed that the chance of winning their case was significantly increased on the grounds of 'gross safety violations' related to the importation of factor treatment from the USA and ignored safety warnings by UK clinicians and civil servants. Instead they were forced to sign a waiver, which has been shown to be unlawful, against any further action as a result of their infections.

Even without proven legal liability the Government still has the option to provide people affected with compensation based on loss and need. Not proving liability has not prevented other countries such as the Republic of Ireland from paying compensation.

The Haemophilia Society's Statements

During the 1980s The Haemophilia Society issued statements reassuring patients that the new factor treatments were safe and to continue using them. We also lobbied the Government to continue allowing the import of products from the USA.

The advice we gave our members was based on guidance from the Haemophilia Centre Directors (now known as the UKHCDO) and from the Government. The leadership and trustees of The Haemophilia Society were misled and, as a result, unwittingly further contributed to the Scandal.

However, we accept that our actions and statements at the time, while well-intentioned and based on expert advice, have subsequently been shown to be damaging to the community and false. For this we unreservedly apologise.

For all people affected by bleeding disorders