

For all people affected by bleeding disorders



THE
HAEMOPHILIA
SOCIETY
UNITED KINGDOM

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Ms Jane Ellison MP
Parliamentary Under Secretary of State for Public Health
Department of Health
Richmond House
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10 February 2015

Dear Ms Ellison

Following the recent publications of the APPG on Haemophilia and Contaminated Blood Inquiry report, and the Back Bench Debate which you attended on 15 January, The Haemophilia Society Board of Trustees have asked me to write to you with our response.

We believe the current system of support provided by the five organisations (MFET, The MacFarlane Trust, The Skipton Fund, Caxton Foundation and The Eileen Trust) funded by the Department of Health to support those affected by the contaminated blood tragedy is not fit for purpose. The Haemophilia Society believe they should be disbanded, and a new mechanism of support created, including a completely different team of people to administer future support.

We also believe it is important that The Prime Minister makes a formal public apology before Parliament dissolves on the 30th March, acknowledging the devastating impact this tragedy has had on so many people. This will be the last opportunity during this parliament The Prime Minister has to make a statement on this issue, and will be recognised as a very positive gesture following the publication of the Penrose Report and recent Parliamentary activity. As shown by the apology made to those affected by the Hillsborough disaster this would be an important step for the thousands of people affected.

As you know, the APPG report showed that overall levels of satisfaction were low with only 31% saying they were dealt with efficiently, 21% stating the support met their needs and 19% that support was given fairly.

We have a great deal of contact with people affected by contaminated blood, and also occasionally meet with The Chief Executive and Chairs of The MacFarlane Trust and Caxton Foundation. The Haemophilia Society also nominate three Trustees to the Board of the MacFarlane Trust. Although we do receive mixed views on the organisations, the overwhelming experience of those we speak to is dissatisfaction, distress or anger at the way beneficiaries of the organisations are treated. Some of this is directed at the Department of Health in terms of the level of support provided, but much is focused on the lack of respect and understanding of the issues beneficiaries face by the

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staff of these organisations. This was also reflected in the many personal stories relayed by the MPs who spoke at the Back Bench Debate.

The experience of The Haemophilia Societies backs this up, including at a recent meeting between myself and the Chief Executive, Jan Barlow and Chair of The MacFarlane Trust Roger Evans, where they expressed the opinion that the Department of Health should wait before responding to Penrose so more people will have died and they will have less to pay out.

This does not in our view, reflect the stance we believe a Chief Executive and Chair of a charity set up by the Department of Health to support beneficiaries of the 15th greatest peacetime disaster in Britain and the worst NHS tragedy in history should hold.

We have not taken this decision lightly as we know any change may cause distress to some people, reminding them of the tragedy they have faced and for that we are sorry. We do however believe this is the only way to ensure everyone affected is treated with the dignity and respect they deserve in the longer term.

There is no easy answer to how a new system of support could be established, but we believe an independent group, with members who have a strong understanding of the impact of this tragedy as well as professional expertise in relevant fields is essential. The Haemophilia Society would like to offer our help in designing a new system of support and appointing an appropriate management team, ensuring any new system is focused on beneficiary need.

We strongly believe the excellent work being undertaken by Alistair Burt MP on behalf of the Prime Minister, and the work of the APPG must not be allowed to lose momentum due to the General Election, and must bring about a significant improvement in the support offered to the thousands of people who live with the consequences of this tragedy daily.

We await your response.

Yours sincerely

GRO-C

Liz Carroll
Chief Executive
The Haemophilia Society

cc
The Rt Hon Jeremy Hunt MP
Andy Burnham MP
Norman Lamb MP
Alistair Burt MP
Diana Johnson MP
Jason McCartney MP
Baroness Molly Meacher

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