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Subject: draft letter to Jane Ellison MP re contaminated blood support
Date: Tue, 10 Feb 2015 14:48:28 +0000

Dear all

Please find attached a draft letter to Jane Ellison MP following our discussion and agreement at the Board meeting.

This has taken me quite a while to construct as it is such an inflammatory subject. There are very different opinions on what should happen, however this is what we agreed. I am sure there will be a serious backlash from Jane, Roger and Anne as of course this has a huge impact on them.

I had a call from Alistair Burt yesterday afternoon, asking that any response we are planning to make happens quickly as he is meeting with Jane Ellison and the Prime Ministers office very soon and any support would be very helpful. He asked my personal experiences of meeting with Jan, so I shared with him the recent experience mentioned here. He asked for this to be included if possible as it is a clear example of attitude – it can of course be removed if people think it is a step too far, however it is factual.

There is no doubt there are people who are very happy with the service they get, and don't want to be reminded of what happened, or the system changed so we must be mindful of that, but a significant number are very distressed.

Alistair said he and the APPG will be reporting that parliament will not accept anything less than disbanding of the Alliance House organisations, so are in line with our response. He is also calling for an apology, and thinks it is possible, with enough support. I also met with Charles Gore from the Hepatitis C trust this week and he stated he believes they should be disbanded.

As this letter will be public, we need to find an agreed text that all will stand behind, so please share your thoughts so we can get it right.

Thanks
Liz

Liz Carroll
Chief Executive
The Haemophilia Society

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Ms Jane Ellison MP
Parliamentary Under Secretary of State for Public Health
Department of Health
Richmond House
London
SW1A 2NS

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 The Prime Minister has to make a statement on this issue, and will be a very positive gesture following the publication of the Penrose Report and recent Parliamentary activity.

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 McFarlane 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 staff of the these organisations.

For all people affected by bleeding disorders

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

The Haemophilia Societies own experience 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. 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

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