

Witness Name: Lynne Kelly

Statement No: WITN3988001

Exhibits: WITN3988002-WITN3988093

Dated: 30 July 2020

EXHIBIT WITN3988081

Wed 31st Oct 2012.

TO BOARD MEMBERS OF THE HAEMOPHILIA SOCIETY.

Dear Trustees,

I have been asked to write to you by the Scottish Management Committee following the Board's decision to adopt and publish its policy on contaminated blood. The content of this letter has been agreed by the Scottish Committee following an emergency conference call held to discuss that decision.

The Scottish Management Committee wishes to state it deplores the UK Board's decision to adopt and publish its policy on contaminated blood against our advice, particularly at this time, with the Penrose Inquiry still to publish its report. We urge you in the strongest possible terms as a participant in the Penrose Inquiry to remove the call for a UK-wide statutory inquiry.

On Monday 29th October the Penrose Inquiry conducted a public hearing, a hearing held as a result of our lawyers call for work on statistics to be completed. Lord Penrose now is considering whether to re-open the oral hearings to address the issues raised.

Haemophilia Society representatives in Scotland are now faced with having to account for a call by the UK Society for a new UK wide Inquiry before the Penrose Inquiry has reported. Given our previous experience of how critically Lord Penrose, the Inquiry Chairman, views such failures in following process and due legal process, we are left with no alternative but to publicly distance ourselves from the UK Board's recently declared Contaminated Blood Policy.

Haemophilia Society Chairman, Bernard Manson, was fully aware the Penrose Inquiry might be reopening. Some weeks ago, he and I discussed the possibility via telephone. The subject of our discussion was the situation concerning the standing of the Penrose Advisory Group, and who would take responsibility for strategy hence forth in preparing the ground to respond to Lord Penrose's report. As far back as my earlier letter to Trustees in May this year I made recommendations in that respect - recommendations which as far as I am aware have yet to be acted upon.

The UK Board's decision to pursue political avenues via the Westminster APPG for progress on contaminated blood, rather than first see through the legal process being followed under the Inquiries Act, via the Penrose Inquiry, directly contradicts and undermines our publicly stated undertaking in Scotland to follow due legal process while the inquiry sits.

Since writing in response to the draft contaminated blood policy and advising against the provisions we have discovered further alarming issues related to how the UK Haemophilia Society's Contaminated Blood Policy was developed.

We believe that the UK Board Trustees should have first consulted the Scottish Management Committee on the proposed policy as it collectively has thousands of hours of experience and an understanding of the implications (and frustration) of what is involved in a formal statutory inquiry and how that can affect those who have been infected, bereaved families, care participants and witnesses. Indeed our nominee to the UK Board was for the bulk of the inquiry a highly able and informed solicitor attending virtually every day on the Haemophilia Society's behalf.

Thompsons, as expert lawyers, were only drawn into advising on the implications of the policy at a late stage, on our initiative, when we had become aware of the intention to press ahead with a call for UK wide inquiry. In refusing to accept Thompsons' advice, the contaminated blood policy is calling for something that is not actually possible - a UK wide inquiry. In terms of the Inquiries Act, a UK wide inquiry can only be ordered by a UK Minister with the consent of the Scottish Ministers. Scottish Ministers are not going to consent to this when there is an ongoing inquiry in Scotland. The policy is therefore fundamentally flawed.

Instead of drawing upon the experience and expertise available North of the Border, the Board chose to 'discuss a slightly earlier draft with campaign groups', few or none of whom have been either visible at the Penrose inquiry or involved in the extensive discussions with witnesses and Counsel and thus experiencing daily the limitations to what a statutory inquiry can achieve and the delays built in during the interim.

Thad verbally indicated a willingness to lead a discussion during the AGM weekend for those campaigners seeking a statutory inquiry, about the real possibilities and limitations of what is involved. That offer was not picked up on.

The so-called consultation process employed on the policy was clearly deeply flawed. Instead of writing directly to Haemophilia Society members or even including the draft in its mailing of September 12th, the draft policy was posted on Society's web site leaving to chance whether members actually looked at it.

There have been several Royal Mail posts to members from the Haemophilia Society over recent weeks, including material on the AGM, which could have been used to include some consultation on the proposed Contaminated Blood Policy and calls for a Statutory Inquiry. These opportunities for wide consultation were not utilised. However, the Board claims it 'wishes to make the maximum effort to consider the views of the membership'. With 32 responses it was clearly ineffective as doing so. Therefore, we would suggest that there is not a majority appeal to clearly supporting a statutory UK wide inquiry.

We view this as a serious failure in governance by the Board. Trustees have not acted independently of the Chair or uphold the Articles, instead filtering channels of communication through the Chair and Chief Executive - a distinctly questionable approach to governance and one which greatly concerns the SMC.

The Society's contaminated blood policy, as it now stands, is one the SMC cannot accept. The situation which has been brought about is the latest in a long list of failures by the UK Board to recognise and understand the situation in Scotland and uphold the 'responsibilities' it claims it has North of the Border.

As trustees will know, there are deep seated and long standing misgivings in Scotland at the Board's persistent failure to have the issues and experiences which concern the haemophilia community in Scotland, brought to bear in the Society's deliberations and decision-taking.

These shortcomings include handling of the World Federation Bid where the Board had to agree that mistakes were made. That the bid was eventually successful was, we believe, largely a result of the

strength and depth of expertise, commitment and enthusiasm in Scotland to progress matters positively for the UK-wide haemophilia community.

Disappointingly, however, this latest development regarding the contemplated blood policy indicates, yet again, that the UK Society does not value, appreciate or understand the very distinct situation, arrangements and environment in Scotland.

The Haemophilia Society is listed on the Office of the Scottish Charity Regulator as having as its main operating location 'out-with Scotland'. We are no longer confident the Haemophilia Society with a UK-wide Board is best placed to act primarily in the best interests of haemophilia patients and their families in Scotland.

We therefore write to give notice that the Scottish Management Committee have agreed to examine the feasibility of establishing an independent charity acting for people in Scotland with bleeding disorders with its main operating location 'within and across Scotland'. We will be actively taking soundings over the next few weeks within the community of people with bleeding disorders as well as potential external agencies, officials, politicians, professionals and sources of funding for what support there would be for an independent charity in Scotland that was totally Scottish based, albeit possibly with an affiliation with the UK Society, if both parties agreed.

We anticipate establishing our favoured position by World Haemophilia Day in April 2013 when time and space have been secured for Haemophilia Scotland in the Scottish Parliament.

In addition to the Penrose Inquiry, some further particular considerations need to be borne in mind by the Board in responding to our notice, particularly if it is minded to act to obstruct our favoured way forward or go so far as standing the Scottish Management Committee down. There are soon to be meetings to be held about (and with) the World Federation of Haemophilia on the 2016 Congress.

If we establish that patients and families in Scotland would like a Scottish based charity to be formed and act in their interests as well as having established with external agencies it is feasible, it would neither be in Scottish interests or those of the UK Society to have a less than amicable split. Therefore the Scottish Management Committee will continue meantime to dispose of our duties such as the forthcoming meeting with Centre directors which we have again been invited to take the chair for following last year's success. People in Scotland with bleeding disorders, particularly those with infections watching Penrose Inquiry developments, have on-going needs which, we believe we can both agree, have to be met during the interim.

Anything less than cooperation between the Board and Scottish Committee could also of course have serious implications for settling arrangements during the forthcoming visit by the WFH and jointly working toward delivering the best WFH Congress ever, held here in Britain in 2016. Failure to continue joint working in the meanwhile would be against everything that people both north and south of the Border strive so hard to achieve.

It is extremely unfortunate that relations between the Haemophilia Society Board and the Scottish Management Committee have deteriorated to this degree. We have on numerous occasions over the past year advised the Society Chair and the London office of growing disgust within the Scottish Management Committee over a number of issues, which have not been properly addressed or

respective. Perhaps, the Society's Trustees were not privy to these, as much of the ongoing problems have been down to poor communications, in that the UK Board did not appear to be listening to the genuine and strongly held concerns of Scottish members and the Scottish Management Committee.

I will be present at the AGM in Birmingham. If any Board member wishes individually to contact me or other colleagues on the Scottish Committee to discuss the above, we are willing to do so.

Yours Sincerely

Bill Wright, Chair

On behalf of the Scottish Management Committee