Witness Name: Medora Ann Hithersay
Statement No.: WITN3206003
Exhibits:
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MEDORA ANN HITHERSAY

I provide this written statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 22 October 2020.

I, **Medora Ann Hithersay**, will say as follows:-

1. My name is Medora Ann Hithersay. My date of birth is GRO-C 1937 and I reside at GRO-C Hampshire GRO-C I provide this statement in my capacity as former Trustee of The Haemophilia Society ("THS"). I became a Trustee at THS in January 2004, shortly after finishing my tenure at the Macfarlane Trust. I have given considerable background information in relation to my experience and employment with both the Trust and THS, in my first statement to this Inquiry (URN: WITN3206001) and in response to the Inquiry's first Rule 9 request (URN: WITN3206002).

2. I have addressed the requests raised by this Inquiry in the sequential order in which they are put to me in the Inquiry's letter dated 22 October 2020.

1. Structure of the Haemophilia Society and your role as a Trustee

Please provide the dates of your tenure at the Haemophilia Society, your role and responsibilities and how these changed over time (if at all).

3. I joined THS as a Trustee in January 2004 and I retired in that role in December 2010, however I had relationships with THS prior to that as part of my role as Chief Executive at the Macfarlane Trust, from as early as 1997.

4. My role entailed attending Trustee Board meetings, discussing the various matters that appeared on the agenda, going to conferences, going to the AGM, visiting local haemophilia societies around the country, including in Ireland and the associate organisation in Scotland. The role also entailed supporting our Fundraiser and his team, and discussing matters connected with the use of funds for THS, and the need for additional funds from time to time for specific projects.

When you joined the Haemophilia Society, and throughout your tenure, what were the objectives and functions of the Society? If these changed over time, please detail when and why.

5. The aim of the Society was to provide information, advice and support to children and adults with haemophilia and their families. Certainly, changes occurred over time, in response to the challenges that members faced.

6. The Haemophilia Society had been established a long while when I joined as a Trustee. The first major change that would have occurred in the life of THS would have been related to Factor VIII treatment, HIV and, during my time as a Trustee, the growing concern and awareness of the impact of Hepatitis C.

7. People with haemophilia who were treated with Factor VIII had known about HIV since probably the mid to late 1980s, and so it was understood and realised by the medical teams treating people that their haemophiliac patients had also become infected with what was referred to non-A non-B hepatitis ("NANBH") . I remember it being described as a mild infection at the time. Its long-term effects were not known, and so not much focus was paid to it. Over time, that understanding changed dramatically when it began to become apparent that the nature of NANBH over a period as long as 30 plus years could move from what appears like a flu-like infection, to a very serious life-threatening condition.

8. THS' objectives have always been, broadly speaking, to ensure they were doing the best for their members. What this specifically was, would change depending on where The Society's efforts were focused at the time.

9. Towards the end of my tenure, THS remained focussed on the need to help families to treat newly diagnosed children with haemophilia, to ensure that they never became disabled in the way that had happened to many older people with haemophilia. However, in addition, they were also wanted to ensure there was focus on the increasingly severe impact of Hepatitis C on their members, and appreciated the need for THS to campaign for more direct help to be made available to them.

Please describe the relationship between the Board of Trustees, Council, Executive Committee and the day-to-day management of the Society.

10. I do no recall there being a specific difference between the Board of Trustees and the Executive Committee. As far as I can remember, the Council was made up of representatives from members of the local Haemophilia Society. Certainly, this was the case in England and Wales. Scotland and Northern Ireland would have had their own structure.

11. Trustees were proposed and elected by members of the Council annually at the AGM, and the Trustee Board was responsible for managing the Chief Executive who in turn would have managed the staff groups. The sub-committees reported to the Trustee Board through the Chief Executive, who had the greatest responsibility to ensure that the day-to-day management of THS was effective.

Please list all the different Haemophilia Society sub-committees, "task groups" and/or advisory bodies that you were involved in and describe the purpose, functions and responsibilities of each committee, "task group" and/or advisory body.

12. The only sub-group of which I recall being an established member was the Resources Committee, which the Inquiry refers to in a later question. I would have been interested in all of the other sub-committees and their reports, but I do not recall being a member of any other.

13. The Resources Committee was responsible for the overall direction of the funds of THS so it would have been very much involved with fundraising efforts. We received a monthly budget from the finance department I believe. This was closely scrutinised, and the Chief Executive and the Fundraising Manager would provide information around budget variances. We would have discussed such things as the need to campaign for funds. We may have discussed the need to approach pharmaceutical companies but I cannot remember specific discussions about this, simply because the process by which we secure their funding, and the areas where they helped THS were already long established when I joined.

14. The Resources Committee would also have been involved in deciding whether or not we should recruit new staff. If we identified a need for a particular staff post, for example, a Communications Officer, then we would have been involved in recruitment. I recall recruiting a new Fundraising Manager during my time as a Trustee.

2. Relationship between the Haemophilia Society and Pharmaceutical Companies

The Inquiry is aware that you were a member of the Resources Sub-Committee [HSOC0013313]. What was the role (if any) of the Resources Sub-Committee in seeking financial contributions from pharmaceutical companies on behalf of the Haemophilia Society? Please provide as much information as possible, including:

- **a. How were financial relationships with pharmaceutical companies formed?**
- **b. Who prompted these relationships?**
- **c. Who were the points of contact?**
- **d. Please provide details on the method of communication between the Society and pharmaceutical companies for the purpose of receiving/seeking financial contributions.**

15. The Resources Sub-Committee would have identified areas where funding was required, and pharmaceutical companies would have responded to this. The Sub-Committee would not have applied directly to pharmaceutical companies for funding. The Chief Executive

and the Chairman took responsibility for that, and I understand those relationships had been long established before I joined THS.

16. The Chairman and Chief Executive were the points of contact. They regularly met with representatives of pharmaceutical companies who were interested in and committed to supporting THS. They would update potential funders as to what THS' priorities were at a particular time, and the Resources Sub-Committee, with input from the fundraising team, would have kept them updated as to what these were. The Chief Executive and Senior Managers, which would include the Fundraising Manager, would identify new projects and fundraising aims. The Fundraising Manager sometimes joined the Chairman and Chief Executive at meetings with potential funders I believe.

17. For example, I remember that a particular need we identified was to promote the support of women who had other blood disorders, although they were still THS members. I cannot recall the specific details, however I know we wanted to reach out to those particular people who were not automatically connected to THS, in the same way as men with haemophilia and their families were.

18. I do not know what the methods of communication were between the Chairman and Chief Executive, and pharmaceutical companies. I expect it would have been through discussion, as specific needs arose, or in response to, for example, an upcoming World Haemophilia Congress, which met every four years. The pharmaceutical companies would agree to sponsor a certain number of THS delegates to attend these conferences, and those delegates could include members of the Trustee Board, members of the Council and THS members.

19. I have been referred to document **HSOC0013313** which are minutes of a Resources Sub-Committee meeting to which I had sent my apologies. I cannot really recall anything about the matters referred to in those minutes.

Please list all pharmaceutical companies that provided direct or indirect financial support to the Haemophilia Society.

20. I cannot remember any names after such a long time.

To what extent did the Haemophilia Society rely on financial contributions from pharmaceutical companies manufacturing and/or supplying blood products? In your answer, please provide as much detail as possible on any of the Haemophilia Society's activities, publications, appointments and staff that were funded or partially funded by financial contributions from pharmaceutical companies. Please describe the level and nature of funding that was being provided when you commenced your tenure at the Society and how that changed, if at all, over time.

21. I think we had come to rely on pharmaceutical companies for routine support with such things as attending overseas conferences and, from time to time, funding a specific appeal or project, or possibly a member of staff. I doubt that they would have provided permanent funding for a member of staff but they might have provided an element of "launch funding" to allow THS the opportunity to determine how useful that particular role may be to them. If the role was thought to be useful they would be kept on, but that would be a matter for THS to fund rather than the pharmaceutical companies providing ongoing funding.

22. I think pharmaceutical companies sponsored a publication, most likely the Bulletin. I cannot remember how often or permanent that funding was. At this distance of time I cannot recall anything more about this.

How, if at all, did the Haemophilia Society's fundraising activities develop over your tenure? What factors or activities, if any, contributed to increasing or decreasing financial contributions to the Haemophilia Society from pharmaceutical companies manufacturing and/or supplying blood products?

23. On the Resources Sub-Committee we would have seen fluctuations in financial contributions on the income schedules and budget presentations. Fundraising activities would be undertaken depending on what had been identified as a priority for THS at the time and, as I have indicated above, this did change from time to time. For example, when NANBH became greater concern within the haemophilia community, the focus of our fundraising and the nature of the particular projects we were raising funds for would

change. The expertise that we would have required and how we would have reached out to members would also have changed.

Please explain any differences in the Society's relationships with the different pharmaceutical companies. For example, were there some pharmaceutical companies that donated more, in terms of frequency and/or amount, than other pharmaceutical companies, to the Haemophilia Society? If so, which ones? Did they have different expectations of the Society? Did they want to fund different activities or functions?

24. After so long I cannot recall anything about these matters that would assist.

What, in your view, were the motivations or expectations, if any, of pharmaceutical companies who donated to the Haemophilia Society? Was there an expectation that the Haemophilia Society would provide anything in return and if so, what?

25. I cannot really answer this question as any relationships between THS and pharmaceutical companies had been established well before I joined as a Trustee in 2004. I expect there was some kind of mutual benefit but I cannot recall how that was expressed, except for instances such as a pharmaceutical company's sponsorship of a THS stand at the World Haemophilia Congress, which would carry the sponsor's brand or logo. Beyond that, I cannot recall any kind of expectations ever being discussed.

A number of the Haemophilia Society Bulletins record which pharmaceutical company funded the production of the Bulletin. Was that record a requirement of their funding? What was agreed in this regard? How was this agreed?

26. I have no knowledge of this. I was not directly involved in any discussions of this nature. As I have said above, these would have been matters for the Chief Executive and Chairman to deal with. The Board of Trustees was somewhat set back from this process. We would have been told what had been agreed or the challenges and outcomes of a situation, but I cannot recall that we would have been told about the finer details of specific arrangements.

Did the Haemophilia Society publish or disseminate any articles or publications in exchange or with the expectation of receiving financial contributions, or any other

benefit, by pharmaceutical companies? If so, please provide details on the nature of these articles or publications.

27. THS publications were produced mainly for the benefit of the THS membership, and they would be targeted at specific sections of the membership where necessary. For example, in one issue there would be particular information about treatment for young children with haemophilia, and in another, members could have been asked for their views on what issues should be raised at Congress. The Bulletin and publications were aimed mainly at our membership. They certainly did not provide any forum for pharmaceutical companies to promote their products, to my recollection.

Did the Haemophilia Society rely on pharmaceutical companies for assistance or support, other than financial contributions? If so, please provide as much detail as possible on the support provided, the specific activities/functions that pharmaceutical companies supported, and the names of pharmaceutical companies involved.

28. I have a recollection that some staff members from pharmaceutical companies would volunteer to help at events like Family Days and fetes, or activities organised for children. I cannot remember any details around this.

3. Knowledge of Risk and Support for Infected and Affected Members

In paragraph 7 of your written statement dated 22 October 2019 you state, *'[t]here was a lot of anger about the situation in the haemophilia community in 1997. There was still a huge amount of secrecy around HIV and contaminated blood. In particular, I knew that haemophiliacs were angry as they had trusted the Haemophilia Centres that had recommended Factor VIII blood products to them. The MFT and The Society believed those treating them had been trying to do their best and they believed Factor VIII was a breakthrough.'* How and when did the Society arrive at this view? What was the basis for that view? Who provided the information on which that view was formed? What influence (if any) did this view have on the Society's actions and decisions?

29. I am not entirely clear on the question being asked by the Inquiry. I did not join THS until 2004 and so I cannot speak to how and why THS formed specific views in 1997. At that time I was employed by the MFT and so I would often hear the views and frustrations of the registrants of that Trust. Infected and affected individuals would have been treated by a particular haemophilia centre, and they would have built up a close relationship with those treating them. I believe that the centre directors and other staff at the haemophilia centres wholly believed that the Factor VIII that they were treating people with was a breakthrough and was doing good. It is unsurprising that, because of the level of trust that existed between the families and their haemophilia centres that, when it appeared that their treatment appeared to be killing them, great anger arose leading to the campaign which resulted in the formation of the Macfarlane Trust. The general public knowledge around HIV and the stigma it carried at the time was a key reason for the level of secrecy around this situation.

30. I think it is important to understand that both parents of children with haemophilia, and those treating them, all believed that the introduction of Factor VIII was a positive step at the time, and it was not until some years later that this changed as the public's awareness about infected blood products, and particularly HIV, developed.

31. Although this was before my time, I would think that THS' knowledge about blood products and the impact this had on people's lives, both positive to start with and negative thereafter, were matters that they would have become aware of from Trustees from haemophilia centres, and members themselves. The Board of Trustees also received advice from the Medical Advisory Board. This knowledge would have influenced THS' campaigning and fundraising efforts, and the knowledge provided to the membership via the Bulletin and various publications.

In paragraphs 36 and 37 of your statement you say it "*took a while for The Society to recognise the impact [of Hepatitis C] on its members. It became a significant issue and concern for both the MFT and The Society [....] Hepatitis C was not given the same weight as HIV until considerably later*". When you were a trustee, what is your understanding of what the Haemophilia Society understood about the:

a. **Risk of Non-A Non-B Hepatitis/ HCV infection from blood products? If this changed over time, please detail when and how;**

b. Health implications of Non-A Non-B Hepatitis/ HCV infection during the relevant period? If this changed over time, please detail when and how; and

c. prevalence of Non-A Non-B Hepatitis/ HCV infection amongst haemophiliacs during the relevant period? If this changed over time, please detail when and how.

32. I did not become a Trustee until 2004, by which time it was widely recognised that the impact of NANBH was becoming a life-threatening condition. I have explained above how general awareness and understanding around NANBH changed over time. When we first began to become aware of it in the early 1980's, it did not appear to have a significant impact on the health of those people who had contracted it. At that time, all of the attention was being given to helping those with HIV, which was proving to be far more serious at that moment. Over time, by the late 1990's and early 2000's, HCV became a recognisably serious condition and severe problems caused by co-infection started to become apparent. Those people who were being treated with combination therapies for their HIV in the late 1990s, found that the co-infection with Hepatitis C had an impact on the liver because of the relationship of the two viruses and the treatments for HIV. So it became evident over time, and certainly over the six years of my tenure at the MFT and, later THS, that HCV was a much more serious and significant condition that had originally been thought. At this point, THS began to campaign for the recognition of HCV as being a very serious and life-threatening illness.

33. I would say that it was not really until the late 1990's that the focus on HCV as a major problem for the haemophilia community as a whole was fully realised. Essentially, the reasons for that would be twofold. Early on everyone was focussed on HIV and, at the same time, the prevalence of HCV or the effect and impact of it did not seem as serious, and so it was overshadowed by HIV. By the time HIV began to be managed in a much better way, enough time had passed for those infected or co-infected with HCV to start presenting with the infection a much more serious and pronounced way, which lifted its prominence in the community and highlighted a serious problem.

34. By the time I became a Trustee at THS, I would say that the balance of awareness of HCV had shifted enough to make a major priority to the THS because of how it was affecting their members.

35. Within the HIV community, the NANBH virus became a very serious and prevalent problem and through co-infected individuals, the awareness of a larger community of individuals infected with HCV grew. Those of us involved in organisations like the MFT and THS began going to conferences related to HCV, as well as those related to HIV, and certainly, as soon as I became a Trustee at THS, I developed a significant awareness of number of people in the haemophilia community who were becoming very seriously ill with HCV-related issues.

Please describe the basis for the Haemophilia Society's beliefs in relation to the issues at 17(a)-(c). What information did they receive that led them to this understanding? Who provided that information? What involved, if any, did the Medical Advisory Panel have in the formation of that understanding?

36. As I have explained above, much of THS' information came from their membership directly, in addition to medical information from the haemophilia centre directors that sat on the THS Trustee Board.

37. I do not recall a great deal about the Medical Advisory Panel. I knew Dr Paul Giangrande and Dr Mark Winter who I had worked with at the MFT. There were other centre directors whom I have met during my time with the MFT and THS, however I cannot remember their names.

38. The development of knowledge around HIV and HCV was obviously a cause for increasing concern for medical professionals, and this would have been fed back to the Trustee Board, although I cannot recall any specific details or timeframes. I think I met a few members of the Medical Advisory Panel at THS AGMs, and I expect they would have attended the World Haemophilia Congress also.

Please describe how the Haemophilia Society's understanding of the issues in 17 (a)-(c) above influenced its actions, giving appropriate examples. If these actions changed over time please detail when and how.

39. During my tenure as a THS Trustee, as HCV became a much more significant issue, the focus of a lot of their work was concentrated on securing a public inquiry in order to get to the bottom of how people with haemophilia had become infected with one or both viruses originating from blood products. This was something that we saw as an absolute priority. That is not to say that, during that same period, THS' work with parents and young children and other people with haemophilia who had not been infected by a virus, did not continue. As I have explained above, THS' focus was responsive to whichever were the most serious concerns racing the haemophilia community at the time.

Statement of Truth

I believe the facts stated in this witness statement are true.

Signed: GRO-C
Dated: 2nd Feb. 2021