Witness Name: R Osborn
Statement No: WITN4017001
Exhibits: 0
Dated: February 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF REBECCA OSBORN

I, Rebecca Osborn, will say as follows:-

Section 1. Introduction

1. My name is Rebecca Osborn and I was born on GRO-C 1975. I live at GRO-C GRO-C Derbyshire, GRO-C I got married to Matthew (Matt) Gregory on GRO-C 2012 and GRO-C GRO-C.

2. I make this statement as an affected wife of my husband who was infected with HIV, GRO-C and Hepatitis C whilst he was a teenager via contaminated blood products. He has provided a witness statement to the Inquiry under witness number **WITN1253001.**

3. **This witness statement has been prepared without the benefit of access to my husband's full medical records.**

Section 2. How Affected

4. Matt has severe Haemophilia A.

5. Matt was initially treated with Cryoprecipitate and then Factor VIII when it became available in 1975.

6. He was treated at Derbyshire Royal Infirmary (DRI) and Sheffield Children's Hospital (SCH) under Dr Wylie, Dr Winfield and Dr Mitchell. His current consultant is Dr McKernan.

7. No information was given as to the safety of the blood products and the risk of exposure. In fact it was the complete opposite in that Matt and his parents were explicitly told that the blood products were safe and that there were no risks. Matt recalls speaking directly with Dr GRO-D and specifically asking the questions around safety and was reassured by him that there was no call for concern.

8. After concerns about Matt's status regarding his HIV, his father repeatedly tried to contact Dr Mitchell at the DRI but all attempts proved fruitless. He tried in person and by telephone. He was left feeling frustrated and ignored so he again turned up at the DRI and spent time trying to locate Dr Mitchell and eventually tracked her down on a ward. He literally had to corner her to get her to admit that Matt was infected with HIV. Almost no information was provided at that time, other than his parents were told that he would only have a couple of years to live and that he should not have sex. That was more or less the sum total of the information. Obviously, the way this was handled was woeful and unkind and left lasting scars on all those involved.

9. Matt was diagnosed with GRO-C in 1976, HIV in 1985 and Hepatitis C in 1991. Dates of infection are unknown but it was prior to 1985.

Section 3. Other Infections

10. I do not believe that Matt was infected with any other infections apart from HIV, GRO-C and Hepatitis C. However, he was warned in later years about the possibility of having contracted vCJD.

Section 4. Consent

11. I believe that Matt was tested without his or his parents' knowledge or consent and without being given adequate or full information and for the purposes of research.

Section 5. Impact

12. I first met Matt in 2011 at a listening volunteer training course for Samaritans. Two things struck me about him; he was very cheerful and he was wearing a T-shirt that said "*HIV Positive*" on it. I was always very grateful for that information because it meant that as our relationship developed, there never had to be an awkward conversation about his status.

13. I know in the past he had always found it difficult how and when to tell people about his infections and about what had happened to him as he felt a lot of shame around it due to the way that HIV had been portrayed in society.

14. As I got to know Matt, it soon became clear that he was one of the happiest people I had met. However, as I started to learn about his history, I understood that he had had to work very hard to be able to come to a place of peace, acceptance and contentment.

15. You will be able to read in his and his families' witness statements of the horrific things he had to endure and it is not my place to recount that story here. Suffice to say, I have immense and enduring respect for him and his parents in the face of such adversity, cruelness and unfairness especially at the hands of those who were supposed to help and care.

16. I can only personally relay information from the time I have known Matt. I know he always regards himself as one of the lucky ones as he is still alive. Despite his positive outlook on life, events have obviously at times been difficult to cope with and have had a severe and lasting impact on all our lives.

17. From a physical point of view, he has always been restricted and has never been able to do the normal things that others take for granted. Haemophilia has obviously caused severe difficulties, but add to that the unnecessary burden of having to live with HIV and Hepatitis C and it becomes quite overwhelming.

18. At this point, I would like to make an important point about the co-infected (those infected with both HIV and Hepatitis C). This is such a small group in comparison to other groups that they can get overlooked but my experience is that it is a deadly combination that isn't fully understood or recognised.

19. As a co-infected person, Matt has struggled with physical aspects only associated with this group. Fatigue, exhaustion, brain fog, weakness, memory loss and other problems can be directly attributable to having both the infections of HIV and Hepatitis C and their interactions with each other including the effects of taking multiple medications. Also, with regards to this, the decision by the BSA to give *"x"* amount to HIV sufferers and *"x"* amount to Hepatitis C sufferers but not to award both to the co-infected was very cruel and demeaning. It effectively meant that if you were co-infected, you received a discount! This has never happened before in the history of financial support for the infected and it had a great psychological impact on Matt. The problem being that the BSA really had and still have no idea about the physical and psychological issues involved in this complex area. At least the Macfarlane Trust always tried to take this account. It would be a huge error, if, at the end of this Inquiry, the co-infected were not recognised as the unique group that they are, often coping with severe health issues due to carrying two infections.

20. Matt has had to sacrifice many things as a result of receiving contaminated blood products. He was told at 16 that he would only have a couple of years to live, that he should not have sex, and that there was no hope of recovery. The psychological impact of this is immense especially for someone who has lived with a life-limiting illness for his whole life as well. Among other things, he lost the ability to pursue his education, which in turn led to a loss of any future career he may have wished to pursue. This left him dependent on the

random financial assistance available from the Government, which for a long time was both non-existent and paltry. Although things have improved in this department over the last few years, it in no way comes near to compensating for the loss of earnings encountered and leaves him feeling reliant on handouts which theoretically could stop at any time.

21. The uncertainty is debilitating at times and the loss of self-esteem in not being able to provide runs deep. On top of this, he has no pension, no ability to access life insurance and worries greatly about my financial wellbeing when he dies as the provision for widows is offensive under the current scheme. He recognises that I have sacrificed a great deal in terms of my career to care for him, and whilst I have done this willingly and with love, I have and will continue to suffer financially.

22. Matt has had the opportunity to have his own children taken from him. This is deeply hurtful and only mitigated slightly by the fact that now he is, and has been, a remarkable step-father to my daughter who loves him dearly.

23. On top of the physical problems Matt suffers with, the psychological trauma is almost worse. He has deep rooted issues around closeness, often feeling intense shame, "*dirty*" and "*unlovable*" as a direct result of the way that HIV was portrayed and the abuse that sufferers experienced which was unfortunately, also exacerbated by the way he was treated by medical staff. I can think of occasions even since I have known him where I have experienced medical staff being offensive about him because of his status. I hope this is down to a lack of education on their part but seems extraordinary to me. I have had to constantly adapt and taken into account these psychological issues to make our relationship work, recognising that he has been deeply hurt and traumatised.

24. Matt has always had a realistic and pragmatic approach to this circumstance and has always been willing to give the benefit of the doubt. But upon investigating things further recently, it has become apparent that there was something very wrong in the way the medical profession handled the whole issue. Apart from the historical examples of the way he and his family were

treated at the time, his medical records show that large parts covering the important dates are missing. Blood tests and results which we now have proof were taken are not recorded but only for pivotal dates. Other records which we know would have been there have also gone missing. This, when considered in conjunction with other testimonies, proves to me that something underhand was happening.

25. I would like to continue the impact section with some concluding and summarising paragraphs. The mental and physical effects of being infected with HIV, Hepatitis C and GRO-C are many. Firstly, having battled with a life limiting and potentially terminal illness from birth (Haemophilia) much energy has been used dealing with the effects of this. Matt has not been physically strong because of constant bleeding. To then be told that you have not one but GRO-C deadly infections is catastrophic. Particularly HIV at the time as there was no treatment available and people were dying quickly. It was effectively a death sentence and added to that was the social stigma around the infection and the instructions not to tell anyone. The burden for Matt and his parents in having to carry this alone was immense.

26. Matt developed peripheral neuropathy in his feet in 1986 as a result of HIV. This has caused several problems, including an inability to walk for long periods and being unable to be barefoot.

27. Fortunately, Matt survived long enough for him to be able to start treatment for HIV when it became available although this was only just in time as his viral load had dropped to a dangerously low level and he was seriously unwell and close to dying. He started his HIV medication in 2004 with side effects of rash, nausea, fatigue and stomach upsets.

28. He also started his Hepatitis C medication in 2004 with side effects including loss of appetite, weight loss, fatigue and infections at the injection site.

29. From what I have seen, Matt's family have been tremendously supportive to him but I know that has come at a heavy cost. His parents had no support and did not tell any of their friends for fear of being socially stigmatised and

outcast. It is hard to understate the fear of HIV at the time and the repercussions of being open about your status. Holding this is very difficult and I am sure that it was one of the factors that led to the decline in Matt's father's mental health and his subsequent death. I know that his mother feels very guilty about being the one that injected him with the contaminated products and although his parents and brothers have always been very stoic I fear that they paid heavily in many ways.

30. For Matt, it was a difficult process to navigate from being told at 16 he would die within a couple of years, to be left with the threat of death hanging over him for his whole life, never knowing when his last year would be. He told none of his friends for a long time and found it incredibly difficult when he finally did start to reveal his status. It stopped him forming meaningful long term relationships and committing. GRO-C GRO-C GRO-C Although his health is much improved now, those kinds of psychological difficulties do not go away and I believe he was traumatised in many ways at a young and pivotal age. He was denied the chance to have children which was devastating and just another example of his choices being taken away from him.

31. As Matt's HIV status was disclosed to him at age 16 with the resulting prognosis not being good, his education was effectively over. Although his parents encouraged him to continue with his education, he did this half-heartedly in the knowledge that it was pretty much pointless as he would be dead in a couple of years. He dropped out of sixth form and never really returned to education, spending his time trying to enjoy as much of his life as possible in the short time he was told he had left. This impacted greatly on his life. When he lived longer than predicted, he found himself in the position of needing to work. This was difficult because he did not have he did not have an education that allowed him to pursue a career and being unwell for large periods of time led to an erratic and eclectic series of minimum wage jobs. Matt is incredibly intelligent and could have been successful in almost anything that he would have liked to have done. The fact that this was taken

away from him has had many repercussions over the years, including self esteem issues, severe financial difficulties and later on the psychological issues of being dependent on the Government for the paltry amount of financial assistance that has slowly been forthcoming.

32. For myself, I have only been with Matt for the last ten years but I have also sacrificed my return to education and the pursuit of a career to be able to provide a stable and loving environment in which I can care for him.

Section 6. Treatment/care/support

33. I refer to paragraphs 23 and 24 of my statement in this regard.

34. Matt has been refused dental care by a number of dentists over the years. Furthermore, any treatment that Matt managed to obtain was always difficult and limited as dentists wanted to avoid doing procedures, especially with the threat of vCJD.

35. I have never been offered any counseling or psychological support as a consequence of Matt's infections. Neither Matt nor his family were provided with any such support.

Section 7. Financial Assistance

36. Matt received the Stage One Payment of £20,000 from the Skipton Fund (SF) in 1990/1991. He then received £26,000 from them in 2003.

37. Matt received the Macfarlane and Eileen Trust (MFET) non-discretionary payments which everyone received. This consisted of two one off payments, paid within two years around 1989-1991, of approximately £20,000 and £25,000. Then, after the Archer Inquiry, set monthly payments were paid to everyone. The MFT payments were discretionary payments which were means tested top up to the MFET monthly payments (after Archer) and one off grants.

38. Matt received ongoing support from the MFT and now receives support from EIBSS.

39. My view about the MFT and the SF were that the grants should not have been means tested and there was under financing of both by the Government. I am also of the view that more money needs to be made available.

40. I have not received any support, financial or otherwise, from any of the Trusts/Funds.

41. I believe that proper life time provision needs to be put in place for widows.

42. **GRO-C**

Section 8. Other Issues

43. I would like this Inquiry to uncover the issues and points I have raised in the foregoing which would provide some closure. I would especially like it if Matt's mother were to still be alive to see the Inquiry come to its conclusion so she can find some peace. Therefore, it is imperative to me that this Inquiry is concluded quickly and not dragged out for years like others have been.

44. It is also important that as a result of the Inquiry a proper and stable financial scheme is put into place that adequately looks after the infected and affected, including widows, for the rest of their life which would at least relieve any financial worries that add to their burden. I think under the circumstances, this is the very least that should be done as nothing can ever compensate for the horrific things that have been experienced by the community.

Anonymity

45. I do not want to apply for anonymity and I do not wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed GRO-C ....

Dated..24/02/20.......................