

ANONYMOUS

Witness Name: GRO-B

Statement No: WITN2007001

Exhibits: 0

Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I, GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B. I was born on the GRO-B 1951 and I live at GRO-B with my husband, GRO-B: H. We have two sons and six grandchildren. I am retired.
2. I make this statement in relation to H who has also provided a statement to the Inquiry. H and I have been married for 48 years. In the first 18 years of our marriage we worked very hard, we bought our home together and started a family.
3. This witness statement has been prepared without the benefit of access to my H full medical records.

Section 2. How infected

4. [H] has mild Haemophilia A; he was diagnosed when he was about 12 years old.
5. When I got to know [H] he would have the odd injury every so often but normally it was something that we could deal with ourselves. On most occasions I would patch him up and he would be fine. It was only if he had serious injuries or tooth extractions that he would require blood products.
6. [H] was treated at the Royal Victoria Infirmary (RVI) in Newcastle when the occasion arose under the care of Peter Jones the Director of the Haemophilia Centre at the RVI. [H] statement shows some of the batch numbers of the blood products he received.
7. As far as I am aware [H] was never given any information or advice beforehand about the risk of being exposed to infection from blood products.
8. In the late 1980s I noticed a change in [H]. He tired easily and his energy levels were constantly low. He was always itching and would scratch himself until he bruised or bled. He always complained that he was developing the flu. Soon after this he started to have terrible night sweats and his joints ached. He became agitated and snappy sometimes.
9. [H] was forced to work less overtime due to the issues he was having. He would come home from work, have a hot bath and then usually go straight to bed as he was so exhausted.
10. In 1987 [H] became jaundiced resulting in his skin turning yellow. He became worse and worse from this point onwards. He found it a struggle to work but we

were in need of the money at the time. He often went to work with hot water bottles strapped around him to ease the pain.

11. In 1992 [H] was made redundant. In a way this was a God send as work had become extremely difficult for him. He was a welder at the time. Earlier in the same year we received the news that [H] had been infected with Hepatitis C (HCV) as a result of being treated with contaminated blood.

12. Life became more and more difficult once [H] was diagnosed. Our sons were only 11 and 12 years old at the time.

Section 3. Other Infections

13. As far as I know [H] has only been infected with HCV. However in early the 2000s he received a letter saying that he may have been exposed to CJD. .

Section 4. Consent

14. I am not sure if [H] was treated or tested without his knowledge, he was not really told what they were doing. However, there are medical records exhibited to [H] statement that shows he was tested. This was seven years before he was told he had HCV so they must have been looking for something at the time.

15. If he was tested or treated for infections before 1992 then it was without his consent and without him having received adequate or full information.

16. I do not know if [H] was ever tested for the purposes of research

Section 5. Impact of the Infection

17. By the 1990s [H] mood and depression became worse. I had to cope with more and more. I had to juggle household chores, part-time work, taking the children to all of their activities such as football, swimming and rugby. I did not have enough hours in the day. The additional strain placed on me led to arguments between me and [H]. I was also caring for him; I had to feed him, wash him, give him medication, even take him to the toilet on really bad days.
18. He became very sensitive and self critical. He would always say that he was 'useless' and a 'waste of space'. He would tell me I was better off without him. This was especially bad when he started his Interferon treatment in 1992/93, it made him so sick. He also lost his sex drive as a result.
19. I often had to strip our bed in the middle of the night as the sweats were terrible, he would shut himself away in the bedroom. He lost his appetite and he was often sick so it was difficult to get him to eat anything.
20. [H] would have terrible nightmares. He would often wake up shouting and wake the whole house.
21. In 2003 [H] was treated with Pegylated Alpha Interferon and Ribavirin as a type of combination therapy, this worsened his condition. He became more depressed, it was a terrible time. It was in the 90s when he first started his first course of Interferon and the children were only young. I cried a lot and have done over the years. There were times when I felt I could not cope with everything and I believed we would have to separate.
22. By this point [H] joints were really bad. He had developed diabetes and he was constantly exhausted. He used to say he felt like a battery, he would start the day fully charged but end up completely flat by around five in the evening. He

became snappy and ill tempered. He lost a lot of quality time with our sons as a result of his pain and fatigue.

23. [H] then went two years without any treatment at all. In this period his symptoms persisted he still had to endure pain and flu like symptoms. He had terrible itching and fatigue. His mood was constantly up and down. I had to work while also filling out all the forms for the ESA, PIPS etc. The applications were being rejected and so I appealed which was very stressful especially considering the circumstances.

24. I was very fortunate that my parents could help us financially on occasions. In the early days before we received assistance from the Skipton Fund we just managed to keep our home.

25. There have been occasions where we almost split up but eventually we managed to work things through.

26. In 2006 Veraferon Pegulated Interferon nearly killed [H]. He ended up with pneumonia and was very unwell. He was rushed to hospital in an ambulance I thought he was going to die. He had to stop the course of treatment, it was just wrecking him totally.

27. By 2008 [H] had developed liver cirrhosis. He was unable to tolerate any viral treatment and developed Hepatocellular carcinoma (liver cancer). The hospital tried a course of Transarterial Chemoembolization and Radiofrequency ablation (radiotherapy) to treat the two centimetre tumour. He had various complications; it was an extremely worrying time for myself and our sons. Fortunately in 2009 after various problems and weeks and weeks in hospital the transplant succeeded.

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28. [H] still had HCV which continued to damage his body and by this time he used crutches and needed to use a wheelchair for any distance.
29. In 2018 a new drug cleared [H] HCV. Hopefully his new liver is not too badly damaged and he still requires check ups every 6 months.
30. Since about 2014/2015 I have suffered from panic attacks. They are so bad that I have thought I was suffering from heart attacks; I have been rushed to hospital several times as a result. I am having my heart and blood pressure assessed at [GRO-B] Hospital and am on anti-depressants.
31. At the moment [H] is on a cocktail of medication. They all carry various side effects. Ranging from physical effects such as stomach aches, general sickness, fatigue, headaches, brain fog now and again, as well as sweats and joint pains. He uses a wheelchair all of the time now and we have had a stair lift installed at home and our bedroom has been adapted so he can have, as far as possible a normal quality of life.
32. [H] still has moments of depression and grumpiness which I have learnt to live with. He has lost his sex drive and feels inadequate at times which feeds into his depression.
33. There was so much stigma and fear associated with AIDS so we did not tell our sons we just said the haemophilia was making their dad bad. However when our sons were in their teens we told them of [H] HCV condition, but they had already put two and two together.
34. We only told two close friends and our parents that [H] had received contaminated blood and as a result had been infected with HCV. They stood by us through the years. But other friends who knew [H] had haemophilia all went their own ways so [H] felt a bit like a leper which added to his depression.

35. Our social life just slowly faded away, apart from a shortage of friends [H] never had the energy. He is usually asleep by 7 or 8pm but he tosses and turns all night.

36. We can no longer go on holiday as a result of [H] illness and the fact that travel insurance is so expensive. Three years ago we bought a static caravan 25 miles from where we live with our sons. [H] enjoys sitting on the decking and has a mobility scooter to enable him to get around the site which gives us something to enjoy together.

Section 6. Treatment/care/support

37. [H] has received treatment from several psychiatrists since the early 1990s although it was always difficult to get any help.

Section 7. Financial Assistance

38. I have helped [H] with obtaining financial assistance and I registered him with the Skipton Fund having heard about it through the Liver North Patient Support leaflet that we received. We learnt about the possibility of financial assistance and applied for it. The hospital helped with the application and completed the forms.

39. [H] received the Stage 1 payment of £20,000 in September 2004. In 2005 he developed cirrhosis and applied for the Stage 2 payment. Dr Agarwell confirmed his diagnosis and he received a payment of £25,000. In 2011 he received another £25,000 and in the same year the annual payment scheme commenced so we feel a little more secure.

40. On my insistence [H] also now has in place, through the Skipton Fund, a pre-paid funeral plan.

41. Neil Bateman of the Skipton Fund was very helpful, in particular he helped us to complete the ESA forms in 2013 and the PIP forms in 2016

Section 8. Other Issues

42. I am hoping this Inquiry will finally disclose the truth in regards to what has happened. The victims of this scandal deserve justice and compensation for what has happened.

43. The years we have lost as a result of [H] receiving contaminated blood can never be returned. The years of pain and suffering he has had to endure can never be remedied. But he, and all others infected and affected, deserve an apology and to be acknowledged.

Section 9. Anonymity, disclosure and redaction

44. I confirm that I do wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

45. I do not wish to be called to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....
GRO-B
GRO-B

Dated: 22 / 08 / 2019