

Witness Name: GRO-B
Statement No: WITN1618001
Exhibits: 0
Dated: March 2020

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 and I live at GRO-B
GRO-B
My date of birth is GRO-B

2. I currently work part time as a GRO-B
GRO-B I am in a relationship with my partner of seven and a half years following a divorce after being together with my ex partner for over twenty one years. I have one daughter who has complex health issues and autism.

3. I was infected with Hepatitis C as a result of receiving contaminated Factor VIII concentrates.

4. **This witness statement has been prepared without the benefit of access to my medical records.** I do not have any of my medical records as it was a long time ago and when I went through my divorce things got thrown away, to include my medical records. I did not have a lot of medical history, partly because it was always a reminder of something that I wanted to try and forget for most of the time.

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5. I have severe Haemophilia A.
6. I believe that I was infected with Hepatitis C in the early to mid 1980s. I also think that I was infected with Hepatitis B because I became immune to this at some point.
7. I was treated at Lincoln County Hospital (LCH) for my Haemophilia and I also underwent some operations here. I occasionally saw specialists in Sheffield at the Royal Hallamshire Hospital (RHH) and the Northern General Hospital (NGH) for other surgical procedures and speciality care.
8. I was treated by two Haematologists at the LCH; Denis Pragnell and Mark Adelman. I have no idea how much or how little they knew about the risks of infection from Factor VIII concentrates. They did not give me any advice or information regarding the same. I believe that the medical professionals should have imparted information to me regarding the risks of infection as soon as they were aware of such risks. However, overall, I would say that the care I received from the Haematology Department was very good.
9. I was informed by Dr Pragnell at LCH that I had been infected by something called "*Hep C*" and that (at the time) medics were unsure as to the likely outcomes of this virus. I was told that it could prove very challenging in some people and complications included the possibility of developing cancer, requiring transplant and death. I think I was also told that a lot of other Haemophilia patients were in the same boat as me.
10. I cannot recall when I was informed about my infection but I believe that I was an adult by this time. I believe that I was given insufficient information and literature to allow me to understand or manage my condition.
11. I felt that the way in which I was informed was quite poor. It was communicated almost as a '*Oh and by the way you have an infection that may well lead to complications in your life or kill you*'. I think

delivered to me more sympathetically.

Section 3. Other Infections

12. I do not believe that I received any other infections other than Hepatitis C. However, I was told that I had possibly been put at risk of vCJD.
13. With every new batch of Factor VIII concentrates I remember thinking that each time I injected myself that this could well be the thing that kills me. Even today I do not like starting new batches.

Section 4. Consent

14. I am unsure if I was tested for various viruses without my knowledge and therefore without my consent.
15. I cannot remember whether I was told that I was going to be tested for Hepatitis C. LCH could have easily tested my bloods with the numerous and regular trips there for appointments, treatments and general problems. This could have been done without me even knowing.
16. I do believe that I was "*treated*" in terms of being given contaminated Factor VIII concentrates without my knowledge. If I had known that the treatment was contaminated I would not have taken it. I was never advised that there was any risk of infection prior to being treated in this way.
17. In reality, I have been treated with a product that was probably known to be infected and therefore I could have unwittingly passed the infection to many innocent people.
18. I believe that the Haemophiliac community were used as research tools; we were human guinea pigs.

Section 5. Impact of the Infection

19. The mental and physical effects of being infected with Hepatitis C were horrendous. My whole life

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I thought that I was going to die within weeks or months. I remember visiting people and thinking *"Will this be the last time that I will see them?"*

20. The virus and subsequent treatment had a real hold over me. The outcome of being infected has been ingrained into and shaped my entire life. The emotional damage has never left me.
21. I cannot recall when I was given Interferon treatment but I do remember that the side effect of this were horrific. The treatment lasted about six months and I experienced severe flu like symptoms, my hair fell out, my joints ached terribly and I felt extremely lethargic. The injections were painful and they made the injection site very sore; which persisted for a number of days afterwards.
22. I would describe the treatment as *"one of the worst things I have ever been through"*. Sadly it did not work and I failed to clear the virus.
23. I therefore still felt that I was going to die very young. I had to live with Hepatitis C for over 30 years and it felt like a ticking time bomb.
Throughout this time, I was acutely aware that the results of my liver tests were progressively worsening. It was a frightening existence.
24. I had to wait a long time until some of the newer treatments, to treat Hepatitis C, came onto the market. I cannot remember the name of the new treatment I underwent but it was a relatively easy process and far removed from the harsh Interferon era. Finally, following completion of the new treatment, I was told that I had cleared the virus.
However, I cannot underestimate how terrible those years of living with Hepatitis were; I wouldn't wish that trajectory on my worst enemy.
25. I now suffer from erectile dysfunction which I am convinced was caused by the severe Interferon treatment.
26. In terms of disclosing my infection to others I can confirm that I did not even tell my mother and father. They would have only worried for me and I

a few other close friends.

27. It was particularly hard after my divorce because I was dealing with the social exclusion from both the divorce and the Hepatitis C. Dating was very hard and I found that the virus acted as a huge barrier to staying positive and carrying on with my life.
28. I was not working when I became infected and I can categorically say that holding a job down whilst undertaking the Interferon treatment would have been impossible. Therefore, for me, the effects of the virus have been more emotional than financial. However, I have spent thousands of pounds on complimentary health measures over the years to try and fight the virus.

Section 6. Treatment/care/support

29. I don't think I faced any obstacles obtaining treatment, care or support although sometimes it was a little harder to access dental care.
30. I have never received any counselling or psychological support in consequence of my infection.
31. I received support from my wife and the few others to whom I disclosed my infection. I did not think that I was going to be around long enough in the very early days and therefore seeking support was not at the top of my to do list.

Section 7. Financial Assistance

32. I received the Stage 1 Payment from the Skipton Fund (SF) of £20,000 about fifteen years ago.
33. I did not receive the Stage 2 Payment because I did not have cirrhosis. However, I do have liver fibrosis and scarring.
34. I used to get a monthly allowance from the SF before their demise.

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35. I now receive the Special Category Mechanism (SCM) Payments from the EIBSS each month together with an annual fuel allowance and support for other things if deemed appropriate.
36. The Haematology Department at the LCH and the Haemophilia Society urged people, including myself, to apply for funding from the Skipton/Caxton funds which I did.
37. The application procedure was relatively straightforward and I found the staff helpful and supportive.

Section 8. Other Issues

38. I want the Inquiry to get to the bottom of any cover ups and to apportion blame to any guilty parties.
39. To knowingly allow contaminated blood to be given to many people and to treat them like guinea pigs is a shameful way to act.
40. Sadly a lot of my fellow Haemophiliacs will not be around to witness any outcome. I am one of the fortunate ones and am grateful to still be here.

Anonymity

41. I 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.

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Signed

GRO-B

Dated.....30/3/20.....

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