Witness Name: John Griffiths

Statement No: W7287

Exhibits:0

Dated:

2022

INFECTED	BLOOD	INQUIRY
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	FIRST WRITTEN STATEMENT OF JOHN GRIFFITHS
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I, John Griffiths will say as follows:-

Section 1. Introduction

- This witness statement has been prepared with the benefit of access to my daughter Joanne's medical records, although I am still waiting for further medical records to be provided.

Section 2. How Affected

3. My daughter Joanne was infected with Hepatitis C and died at the age of 39 years. Joanne had received a blood transfusion at Great Ormond Street Hospital after she had an operation for her spine to be fused. Joanne had been born with health problems and due to scoliosis and had to have a rod put into her spine. She would have been 12 years old at the time she had the surgery.

- 4. As stated, Joanne had a blood transfusion following surgery for her progressive scoliosis at Great Ormond Street Hospital, when she was around 12 years old. The blood she received during the transfusion had been infected with Hepatitis C and as a result she contracted the virus.
- 5. I do not recall being told anything at the time of the transfusion. We found out about the infection in 1995 when due to the look back review, it was identified that Joanne had received blood from a donor who had tested positive for Hepatitis C. Unfortunately, tests confirmed that Joanne had been infected with Hepatitis C as a result of receiving infected blood.
- 6. Joanne was infected with Hepatitis C (HCV).
- 7. Joanne was an adult by the time her Hepatitis C infection was identified. The Blood Transfusion Service had been reviewing records of donors who had been identified as having Hepatitis C and so Joanne was traced as a recipient of an infected batch of blood. As soon as the consultants who were looking after Joanne for her other health problems were told about the Hepatitis C risk, Joanne was informed and tested.
- 8. Treatment options with anti-viral medication discussed, but Joanne decided that she was fine as she was and did not want any form of treatment for the Hepatitis C at that stage.

Section 3. Other Infections

9. To the best of my knowledge Joanne did not contract any other infections, other than the Hepatitis C as a result of being given infected blood.

Section 4. Consent

10.To the best of my knowledge, Joanne was not treated or tested without her knowledge or consent. I believe she would have been given adequate information when it came to testing.

Section 5. Impact of the Infection

- 11. It is probably helpful to set out some background about Joanne's health. She was born by emergency caesarean section and within a matter of hours she was transferred from Ashford Hospital where she had been born to Harefield Hospital as she didn't thrive. She had what is called a congenital heart block. She was eventually seen at Great Ormond Street Hospital where they inserted wires so she could have a pacemaker fitted if she continued not to thrive.
- 12. In the end, they took the wires out. The combined effect of the operation she had we think was what led to the muscular damage leading to scoliosis. She spent a couple of years where we had to put her into a corset which was very distressing and then eventually, she was sent to the QE2 Hospital for Children at Mile End and she had what can only be described as a tortoise shell fitted, so her arms and legs stuck out, but otherwise she was in what resembled a tortoise shell. As she grew, she had to have that replaced a few times.
- that Joanne had a hole in the heart, something that was also missed by GRO-D

 GRO-D Hospital as well. Joanne was diagnosed with having a hole in the heart because in the course of having the pacing wires removed some blood debris got into the hole in her heart and she had a stroke. So, we were in a situation where Joanne has got a severe curve of the spine, she has got a congenital heart block for which she did have a pace maker put in in the end, the tying off the patent ductus did not bring her blood pressure down so she had strokes. We were told she may not walk beyond her mid teenage years. She was however a feisty little thing and despite all of that she had to cope with, including her failing heart, a distended liver, enlarged heart, she was fighting all

- sorts of issues and then the letter dropped through the door about the Hepatitis C so you can imagine the sort of effect that had on her and those that loved her.
- 14. We had got used to the fact that she may not live much beyond 40 if she was lucky, but by this stage she had got married, had a job, a house, she had friends and was living a life when suddenly she had this extra Damocles hanging over her. This meant that every time from then on, for the best part of 20 years when she attended hospital, she was waiting to hear whether her Hepatitis had developed to full blown cancer. I am not able to read the blood results accurately but from what I have seen I don't think it ever did develop into cancer, but her liver function was affected, and it was getting worse.
- 15. Joanne did worry about the Hepatitis C infection and its impact on her liver, it was an incredibly heavy weight on her, her husband, her mum, her brother and myself as well as everyone who knew her. It seemed incredibly unlucky for someone so ill in so many other ways to receive this further thing to worry about. She had a dreadful time. It did eventually fade into the background and Joanne tried to get on with her life, however there were times when she really cried at home, sometimes she would have a few glasses of wine to cheer herself up she was so worried about her condition.
- 16. As a parent, you want life to be perfect for your kids, it was terribly unfair given all of the issues Joanne had to deal with, I was full of admiration how she dealt with it all, but then that letter, after years of being accustomed to her other issues, before that letter there was hope that she could have a heart/lung transplant, but even if she had that she would still have the nasty sinister disease in the background which would have still killed her, whereas before the Hepatitis C diagnosis there was still hope, hope that she might get a heart lung transplant that would transform her life. The Hepatitis C was permanent, it was a death sentence.
- 17. We hoped that it would be possible for Joanne to have a heart lung transplant, Joanne was only 6 stone, she was very small, she was only 4ft 9" and it is possible she wouldn't have had the transplant if they felt she wasn't strong enough to survive.

18. Joanne had wanted to be a teacher but her health problems meant that she was not strong enough, although a lot of this related to her heart condition, I am sure the hepatitis infection or the knowledge of her infection impacted on her, it certainly would have contributed to her lack of energy.

Section 6. Treatment/care/support

- 19.1 do not believe that Joanne faced any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with Hepatitis C.
- 20. From a personal point I know she felt it important if she was likely to form any physical relationships that she told them she had Hepatitis C. Before she married Jon, there was one boy she was keen on who on being told she had Hepatitis C ended the relationship immediately. It was quite tough on her and would not have done her confidence any food, it made her think she might not have a boyfriend or normal sexual relationship, but then she found Jon.
- 21.I do not know if Joanne had counselling, or any form of formal support, although when she saw the doctor she was under for the whole of her life and went to hospitals for her regular checkups, I am sure she would have had discussions about the Hepatitis C even though the appointment may not have specifically been to discuss that. She had regular blood tests to check her viral load and liver function as she did not want any treatment for the virus given she felt it was not causing her any problems.

Section 7. Financial Assistance

22. Just before she died, Joanne received £20,000 from the Skipton Fund and then received a proportion of the first annual support payment for the year in which she died.

- 23. In terms of how she found out about the Skipton Fund, I believe someone in the family read about it and told her. I remember I steered her through the process, although to be honest her death rendered all that knowledge unimportant and I have shoved it to the back of my mind.
- 24.1 do know that EIBSS accepted that Joanne had Hepatitis C, they now have the Skipton records and have invited Jon to apply for the funeral grant and the bereaved spouse payment and I am assisting him in making those claims.

Section 8. Other Issues

- 25. For Joanne's relatives, we were happy that she was managing to cope with her other illnesses and appeared to be living pretty much a normal live without very much support from her family. She had her husband, and the Hepatitis C was an additional issue. It increased the psychological support she needed from everyone in the family. It made our hands on parenthood last longer than it should have done.
- 26. As a patient you expect what is being pumped into your body is safe.
- 27. Joanne did receive payments from the Skipton Fund, however no one informed us that support may have been available to her family after her death under the EIBSS scheme. It would seem they decided that it was too big a job to try and track down those who might be eligible for support so decided to sit back and wait for those who were entitled to hear about the scheme. I find this scandalous. So many people, including Joanne's husband, were entitled to claim but had no idea they could. It was just by luck we as a family found out about it. There appears to have been no campaign whatsoever designed to publicise the EIBSS payments. I think this is shocking. I have recently submitted Joanne's husband's claim form to EIBSS which will take around 30 days to process. It would appear that Jonathan is entitled to regular payments, and has been entitled to those payments, without his knowledge, for some time. They are not however back dated and so in my view it means that the interim

payment recommended by the Inquiry simply replaces the EIBSS payments he could have been receiving for some time.

Anonymity

- 28.1 wish do not wish to remain anonymous.
- 29.1 do want to give oral evidence to the Inquiry.

Statement of Truth

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

	GRO-C	
Signed		