

Witness Name: PETER BURNS

Statement No: WITN2732001

Exhibits: 0

Dated: MARCH 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PETER BURNS

I, PETER BURNS, will say as follows:-

Section 1. Introduction

1. My name is Peter Burns. I was born on [GRO-C] 1951 and I live at [GRO-C]
[GRO-C], Northern Ireland [GRO-C]
2. My wife, Helena Laureen Burns (born on [GRO-C] 1949), was infected with the Hepatitis C Virus (HCV) from contaminated blood products. She died on 25th November 2016, aged 67, having developed liver cirrhosis and hepatic encephalopathy. HCV was the instrumental cause of Helena's death. HCV, bronchopneumonia, metastasis ovarian cancer and diabetes type 2 are listed on Helena's Death Certificate.
3. This witness statement has been prepared without the benefit of access to my wife's medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

4. Helena was infected with HCV when she had a blood transfusion at the birth of the last of our six children, born by cesarean section at The Mater Hospital, Belfast in GRO-C 1986.
5. Our last two children were born by cesarean section. Helena was not informed that she had been placed at risk at any time before and after the blood transfusion and we had no idea that she had HCV until in or around 2004 or 2005 (nearly 20 years after being infected with the virus)..
6. Helena had a number of health issues around that time and we attended a number of medical appointments together. I was better able to absorb information than Helena. I have a good memory and asked questions at appointments. Helena sometimes asked to be reminded of what was said afterwards and I would be able to tell her or clarify what was said. Helena had some severe facial pains after having dental treatment and we paid privately to see a consultant after Helena's dentist had taken x-rays and pretty much eliminated any cause to do with her dental treatment. We saw a Consultant (Dr Drake I think) at the Belfast City Hospital and she suggested a blood test. Helena was sent to the haematology department and we were subsequently told that Helena had HCV. We did not really know what HCV was. No-one ever sat us down and told us what it was and gave us any information or advice in relation to managing it. Around the same time (August 2005) Helena was diagnosed with breast cancer and our thoughts were pre-occupied by that. I remember that the two departments were adjacent to each other.
7. It was some time later that we were told of the cause and source of the HCV. Helena had never worked with sharps or injected drugs and she had no tattoos. Dr Drake suggested a blood transfusion as being the cause of the infection. Our GP, Dr Sweeney, confirmed it was from the blood transfusion during the final cesarean operation in GRO-C 1986 that the infection happened. I was told that Helena's medical notes and records for any time

period older than 7 years had been destroyed. Dr Sweeney had a note of the transfusion in GRO-C 1986 and said that Helena would have had a minimum of 3 units of blood at that time. It also helped that he was working at the Mater Hospital when Helena had the transfusion and he remembered it.

8. We were given no advice in any shape or form about how to deal with the infection. During the last four years of Helena's life I stopped working and looked after her full time, day and night. I gave Helena injections, and no one told me to be careful. Nobody from the medical profession explained to us just how bad HCV was and the precautions needed to be taken. The attitude was really blasé.

Section 3. Other Infections

9. I do not believe Helena to have received any other infections than HCV.

Section 4. Consent

10. We were not given adequate information about the blood test. We did not know that Helena would be tested for HCV and we did not know what it was.

Section 5. Impact of the Infection

11. The facial pain (neuralgia) was bad for Helena. To the day she died, she was in pain and we never found out what had caused it. We were told that the dental work may have displaced a nerve or nerves. I do not know if the HCV played a part in it. Helena was given various medications for pain relief, Amitriptyline, being one of them. The drugs were horrendous for her on top of everything she had to put up with.
12. Helena's cancer treatment took precedence over the HCV. She had an aggressive form of breast cancer and had a mastectomy. A year later in July 2006 she was found to have secondary ovarian cancer. She then had chemotherapy and endured all the side effects of that treatment including

nausea and losing her hair. There was no question of Helena having any HCV treatment at that time. She was given Herceptin and we were told that the cancer was in remission.

13. We were then in a position to try to address the HCV. We saw a liver specialist, Dr MacDougall at the Royal Victoria Hospital, Belfast in or around 2007. Helena had developed liver cirrhosis and we were told that there was no way back. We were told that the only treatment available was Interferon treatment which apparently had the same (or worse) side effects than chemotherapy. It was a 48 week treatment with nothing better than a 40% success rate. Once you start the treatment you cannot stop it. We were told that Helena was not in good enough health to endure the treatment. She just wasn't fit enough for it.
14. We had had no idea of the implications of having HCV when we were first told of it and just how serious it was. I asked Dr McDougall if there was anything else that could be done. He said that the only solution was a liver transplant. In order to get a liver transplant you must be almost at death's door and yet fit enough to withstand the operation. The doctor did not think Helena was fit enough. It was devastating to hear. It was really just a watching brief after that with Dr MacDougall checking Helena's blood. Dr MacDougall had a nice manner about him. I spoke to him without Helena knowing and said "give her all the hope you can" but there was no light at the end of the tunnel.
15. Helena developed hepatic encephalopathy (the toxins the liver is unable to process have a detrimental effect on the brain) and her brain function was badly impaired with bouts of confusion, memory loss and difficulty with speech. Her immune system was seriously diminished and she had severe fatigue as well as having to endure major side effects from her medication. Helena had 10 years of life from being told of the HCV diagnosis. For the last four years of her life, she was confined to a wheelchair and almost entirely

bedridden. I had to use a hoist to lift her in and out of bed to use the toilet (commode). I had to feed her because of tremors in her hands.

16. This serious reduction in her quality of life had a major effect on her mental state because before the infection started to take its toll, she had been a very vibrant, outgoing person who raised our six children while I went out to work. She suffered from serious periods of depression and it affected her so greatly that our children should see her in that state as she was always a strong influence in their upbringing.

17. Helena was a good looking woman, a beautiful woman. She was always very fussy about her appearance and wore good clothes. She was a lively person, the life and the soul of the party. She was spontaneous and full of fun, surprising me by booking a weekend to New York for us on a last minute unexpected basis. She was also a very capable, independent lady. She was the typical Irish matriarch, running a household of eight, laying down the law and taking care of the family finances. She had common sense and good advice in abundance. It was terrible and demeaning for her to have to rely on me for her personal care and to have all sense of control taken from her by the illness. The illness left her ravaged and racked with pain.

18. I did not, at first, know what was causing her bouts of confusion and erroneously thought that she was developing dementia. The stress and strain of it all caused us to argue. We had terrible rows. She seemed to deteriorate before my eyes. Some days she did not know what day it was or who had come to visit her. A geriatric consultant twigged on to what was causing the problem and the importance of regularly emptying your bowel if you suffer with hepatic encephalopathy to minimise the toxins in the body. No-one had previously warned us that that might happen. As a result Helena had to take strong laxatives, resulting in accidents that caused further upset for her.

19. Helena and I were together 47 years. I worked in construction (very often overseas). I 'followed the money' as they say. Helena ran the household and

brought up the children. When Helena was diagnosed with HIV and cancer, I worked closer to home as a taxi driver. I was able to work nights as some of my children were at home to keep an eye on Helena. Two of my sons are still at home with me. In the last four years of life, I gave up working to care for Helena.

20. I did not fully appreciate the psychological strain that I was under. I was so focused on Helena that I did not realise that my own health was suffering. I was always a fit man and I did not realise that I was going down hill myself. I have started now to take better care of myself but I am still not right.

21. I have three brothers in Australia and I was persuaded to visit with them this October. It is not the same without Helena but I was pressed into it. I am lucky that I have my family but I have no desire to socialise with anyone outside the family any more.

22. We sat down with James, our youngest son, when we found out about Helena's HCV and made it clear that he should not feel bad because his mother was given the transfusion at his birth. We are an open family and talk about everything. We are very close. They all either live with me or locally, no more than 10 minutes walk from my house. I am very lucky to have them. Helena's death is a huge loss to our family. Helena was a strong individual and she was no shrinking violet. She would have been here laying the law down to her children, even though some are parents (and one a grandparent) now themselves, if she had been here and in good health.

23. Helena was not treated well by some of the medical professionals looking after her. She was often treated like she was unclean and had a warning bell around her. Two nurses refused to treat her. It was awful because she was infected with HCV through no fault of her own. Some of the hospital staff had no understanding of what HCV was. She had her PICC line pulled out and left lying on the bed on one occasion and I told the nurses "HCV can't be transferred to you through that". They had to try and go back into a vein to re-fit it.

Section 6. Treatment/care/support

24.No counselling or support was ever offered. No-one so much as ever sat us both down to provide us with information and advice about HCV.

Section 7. Financial Assistance

25.It took the Skipton Fund around 18 months to accept our Stage 1 and Stage 2 applications and make the payment. The onus was on us to provide proof that Helena was infected with HCV from blood products. Helena wanted to abandon it but I am more tenacious. The hospital records only went back for 7 years and it wasn't worth me paying the £50 administration fee for records that did not cover the period in question. They were going to be sent to me before I checked how far they went back. Our GP, Dr Sweeney, verified the claim. The Stage 2 Skipton Fund payment was made for the development of cirrhosis. We also received a monthly amount.

Section 8. Other Issues

26.There are no issues.

Anonymity, disclosure and redaction

27.I do not wish to apply for anonymity and I understand this statement will be published and disclosed as part of the Inquiry. I am prepared to give oral evidence.to the Inquiry if required.

Statement of Truth

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

Signed. GRO-C...

Dated 28/03/2019

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

This witness statement has been prepared without the benefit of access to any of my wife's medical records. .