

Witness Name: Mark Humphries

Statement No: WITN3039001

Dated: 23<sup>rd</sup> April 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF MARK HUMPHRIES

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I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 17<sup>th</sup> April 2019. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Mark Humphries, will say as follows: -

#### 1. Introduction

1. My name is Mark Humphries. My date of birth is GRO-C 1961 and my address is known to the Inquiry. Not Relevant

Not Relevant

#### 2. How Infected

1. I received treatment at the University Hospital of Wales, Heath Park, Cardiff (UHW). I had multiple courses of chemotherapy (7) followed by

sepsis and then remission. I had an autologous transplant to treat my Myeloid leukaemia and whole blood transfusion and blood related products.

2. As a result of these blood transfusion/blood-based products I contracted hepatitis C between 1985-1989, but more likely it was when I was in UCL London from 1987-89.

### 3. Other infections

1. I am not aware that I had any other infections other than hepatitis C and sepsis between 1984-1987, although my gallbladder was removed before hepatitis C was diagnosed as the medics believed that might have been the cause of me "feeling unwell".

### 4. Consent

1. I do not have any knowledge as to whether I was treated or tested without my knowledge, or consent without being given adequate or full information or for research.

### 5. Impact

1. Before I was diagnosed with Leukaemia in around 1984-1985 I was quite driven. This was due to the education that I had received. When I arrived at secondary school, I was placed in the lower of the two remedial bands; I progressed to the lower of the two middle bands which allowed me to take GSE "O" levels. I defied teacher predictions and ignored their advice to follow a more practical academic route.
2. Having been successful at "O" level meant that I could do "A" levels against the wishes of some teachers. At "A" level I again exceeded their predictions to pass "A" levels to go onto University. I intended to

continue with my success in my career; however leukaemia cut this short when diagnosed in 1985-86.

3. Immediately after my successful treatment for leukaemia and during the period 1989-90 I considered going into teaching. However there were continued issues with my health. I was aware that something was wrong with my blood and I struggled to come to terms with admitting to having my condition when filling out application forms which at that time required statements about the applicant's health. I can recall that this was the time of the AIDS scare and the negative adverts that were constantly on TV.
4. I was unable to go straight back to full-time work, it had to be a gradual phased return. Initially I worked for a few days a week at a local Woolworth Stores. During this period, I relapsed and my Consultant Dr Whitaker asked me to go to the Whitchurch 'Sanatorium', Cardiff. This came as a shock to me; I was not told or prepared to be sent to a Victorian 'mental institution'. I discharged myself and nothing further was mentioned of this by my consultant. However, I did feel that I had become institutionalised and struggled to come to terms with my new out of hospital situation.
5. In 1990 an opportunity came up with the Welsh Development Agency (WDA) in London running a product development centre. This was much less physical and after a few false starts I was working full time. Whilst in London I made new friends and regained my health with friends who understood what I had been through.
6. I returned to Cardiff to work as a Retail Consultant. I bought a house and continued to regain my health. I started playing badminton again and having enough energy to do longer walks.
7. I started getting my career back on track and I was successful in getting the job of Retail Manager at the National Museum of Wales (NMW) which was a senior role running the commercial arms of the

NMW branches. Here I met my wife in 1992 and got married in 1995 and settled in Cardiff. Despite still going for regular leukaemia check-ups I was feeling positive and making a success of my life.

8. Our son was born in 1996. During the period my wife was expecting our son we both saw the Panorama programme on the hepatitis C tainted blood scandal and how many patients were unaware that they may have contracted hepatitis C. I can recall thinking with disbelief "I think that's me".
9. A few days later I made an appointment to see our local GP and asked to be tested for hepatitis C and a couple of weeks later the results came back as positive. This light bulb moment filled in all the gaps of why I felt so ill after being given the all clear for leukaemia in 1987. The life threatening reactions to the transfusions and blood products I received should have alerted the medical professionals treating me that something wasn't right.
10. I was tested positive GRO-C  
GRO-C. I had a liver biopsy that showed considerable scarring (cirrhosis) however my blood counts were not of concern and were only marginally outside of the normal range. This had a significant impact on me and I was aware that I had something that could take me away from my wife and new family. I was devastated with the knowledge and its possible implications. Despite wanting more children and a sibling for our son we no longer tried for any more children and took precautions against accidentally spreading the disease. My long term health was unknown and the risk and burden of bringing another child into this world was too great for us.
11. My son knew not to use daddy's tooth brush because he had something nasty in his blood. I was offered treatment of Interferon and Ribavirin. At that time the treatment was injections which my wife administered. Wherever we went for six months, to friends or family I

had to refrigerate the Interferon and take a sharps box with me. After five months I relapsed and the hepatitis C returned.

12. I did approach legal advisors with regard to my infection, but was advised that they were unable to take it on.
13. The treatment from Interferon left me feeling tired and mentally less alert than usual. I lost resilience when it came to playing sports and with what I could do with my young son. I had to always think about how I would feel after any significant exertions.
14. In 1999 I was approached by another company to be the Managing Director of a small food/retail and distribution company. There was a lot more pressure. At the same time I started another course of Interferon, Ribavirin and another Amantadine I became very tired, depressed and stressed. This was worsened by being made redundant. I felt a change of career would help and applied to go on a PGCE course. New HR regulations now meant that I no longer had to disclose my health condition. I took six months off work and regained my health prior to starting my PGCE in September 2003.
15. On successful completion of my PGCE at Swansea University I started teaching Geography at Brecon High School in Brecon. During my time as a Teacher I started two more courses of Pegylated Interferon and Ribavirin, both of which failed. My attitude now towards my career was always health orientated. I aimed to minimise stress by not taking on senior management responsibilities, if I could avoid it. I self-limited my career ambitions, this has meant that I sometimes feel that if I had not had hepatitis C that I would have taken more steps towards possibly going into senior management, but the uncertainty over my health has always been present. I took voluntary redundancy in 2018 and now work part time as an Examiner and Moderator for UK National Exam Boards.

16. I always felt I had more to give and felt a negative sense of under achievement permanently hanging over me. It was like living with a bomb that could go off at any time. Every three monthly appointments involved blood tests, fibro scans, CT scans, full blood counts etc. No official time was spent on advising me how to live with hepatitis C, other than being told not to have unprotected sex or share tooth brushes.
17. For what I have been through I would have liked to have been able to spend more time gardening, playing a greater physical part of my son's life where I may have helped/ coached in his sporting activities, carried out DIY projects. All these normal life tasks I was unable to do to the extent I wanted to.
18. Apart from the personal stigma I felt with knowing I had a contagious disease the outward label also played heavily on me. An example of this would be the little yellow sticker on my notes which altered the approach to me of any person viewing my charts or records.
19. Although I have been given the all clear I still get very tired and regularly suffer with severe stomach and Irritable Bowel Syndrome (IBS) type symptoms which I believe is directly linked to the removal of my gall bladder and the early treatment I was receiving more specifically with Interferon. This limits what I can eat and I need to be close to a toilet as I sometimes need to use it at very short notice.
20. When the pathology results returned it was found that my gallbladder was healthy and as a result of this vital organ's removal I now sometimes suffer from loose and watery stools, accompanied by a sense of urgency to go to the toilet. I quite frequently have to go to the toilet "immediately" and many times I've had to go in the bushes if I'm on the golf course. This is an extremely embarrassing condition for me. This limits visits to restaurants and socialising as I always need to assess where the nearest toilet is.

21. Hepatitis C has been the all-encompassing event in my life. I am now retired and feel that I had been robbed of making the most of a post leukaemia life. Being successfully treated was a blessing, but then I was cursed with an illness that lasted and was present with me in an active state until I was 56 years old. This should not have happened. My wife and son have also had to live with the uncertainty of my illness and the possible consequences.
22. I believe that whilst being treated in London I was kept in the dark about having hepatitis C, that medical staff were sufficiently vague saying that Non-A Non-B was a possibility along with a whole host of other possibilities.
23. From my medical notes reveal that I was treated with Interferon, but I was not aware of why these were given. Hepatitis was only ever a possibility and I was alarmed to find that my medical records mention hepatitis Non A and B several times but I am adamant that this was never a confirmed diagnosis. I refer to my own request that I be tested in 1996 as a result of watching the Panorama documentary.
24. I also believe that it was known that the blood products coming from the London Blood Transfusion Services were tainted. I had no such reactions I believe (memories can be vague) to transfusions from the South Wales Transfusion Services, but the violent reactions in London were sometimes life threatening and deeply unpleasant for my parents to see. There appeared to be no medical concern about what was happening.
25. My life for the past 32 years has been framed by hepatitis C where every aspect of life has revolved around this condition. I have even had to change my diet to avoid fatty food which causes agonising stomach cramps, which limits what food I can eat and the choice of restaurants we can go to.

26. In 2016 I communicated with Mark Drakeford the then Health Secretary at the Welsh Assembly and also Kirsty Williams, another politician at the Welsh Assembly, to see whether I was eligible for the new anti-viral hepatitis C drugs. Mark Drakeford was unable to offer any support and Kirsty Williams continued to ask questions in the Assembly.

## 6. Treatment/Care Support

1. The treatment included Interferon Monotherapy, Interferon and Ribavirin, Interferon, Ribavirin and Amantadine and also Pegylated Interferon and Ribavirin, between 1996 and 2001. Support during this phase was minimal, advice on how to live with the disease referred to not having unprotected sex or to share a tooth brush.
2. In 2017 I was granted the right to be treated with Sofosbuvir which cured me of active hepatitis C but I will always test positive for the virus.
3. My liver has been damaged and was diagnosed with fibrosis. I am surprised that following nearly thirty years of treatment that I do not have at least yearly follow up assessments by either UHW Cardiff or by my GP. At one time I was very tired and felt that Hepatitis C had relapsed. I had a blood test and the surgery said that I tested positive. I spent a half hour feeling awful only to realise myself that they must have carried out the wrong test. The GP then called me for the correct blood test. The latter was clear.

## 7. Financial Assistance

1. I have received £20,000 from the Skipton Fund in 1997. However, following a successful application in the last six months I have been receiving payments from England Infected Blood Support Scheme (EIBSS) under the SCM scheme.



## 8. Other Issues

1. It is important to me that all stakeholders reveal what they knew and when they knew it. That there is responsibility for the actions and also the inaction.
2. I would like to know the rationale for why I was sent to an AIDS ward and a mental institution, why I was told to go home and rest when I had a serious medical condition and why it took Panorama, a TV programme, for me to find out that I had hepatitis C. Given that the tainted blood was used in the eighties it should have been a matter of recourse for the medical authorities at UCH London and UHW Cardiff to contact patients who had received blood transfusions to screen us and ascertain the size of the problem.
3. Watching the documentary on TV was that light bulb moment for me where I knew that what I had been suffering for all these years was hepatitis C that came from the transfusions of from contaminated blood whilst I was being treated for leukaemia between 1985-89.
4. The government and NHS have been reluctant to identify the problem for fear of being found out for being medically negligent.
5. It also upset me that when I applied for my medical records from the UCL hospital it contained a number of negative and false comments about my dad, who was my rock during this very traumatic and scary part of my life. He was a well-respected member of society, he was the editor of Wales's largest newspaper, the Western Mail, and he had been invited to 10 Downing Street to meet with Tony Blair as he had raised over £1m for a donor match charity. The notes implied that he was "aggressive" and the general tone was not pleasant for someone I have great respect for.

**Statement of Truth**

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

Signed GRO-C

Dated.....23/4/19.....