Witness Name: Julia Lock
Statement No.: WITN4099001
Exhibits: **WITN4099002 - 11**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JULIA ELIZABETH LOCK

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 June 2020.

I, Julia Elizabeth Lock, will say as follows: -

Section 1. Introduction

1. My name is Julia Lock, my date of birth is GRO-C 1978 and my address is known to the Inquiry.

2. I can confirm that I am not legally represented and I am happy for the Inquiry to take my statement.

3. The Inquiry investigator has explained the anonymity process to me NOT RELEVANT NOT RELEVANT There is a stigma to vCJD and I do not want to be viewed as if I have this disease; I don't want to be treated differently and I don't want the sympathy. I am not ashamed, but I do feel embarrassed

4. The Inquiry Investigator has explained the "Right to Reply" to me. I understand this to mean that any significant criticism I make of a medical professional, organisation or other person the Inquiry considers necessary to inform, may be contacted for the purpose of responding to the criticism.

5. My statement will describe how I was wrongly diagnosed with Haemophilia, a Factor XI deficiency in 1993, and the subsequent major issues this has caused me to date. I did not find out about this error until 2010 as a result of my taking legal action against Betsi Cadwaladr University Health Board ("the health board").

6. I had an active and happy childhood. In 1995, I worked from a young age and recall my first Saturday job at Dorothy Perkins. In 1997, whilst studying for my A Levels in Art & Design and Technology, I worked at the local Tesco store in GRO-C on the weekends until 1998. I also worked at the local polling stations and recall my last time doing so in 1999.

7. From 2000 to 2003, I studied for a Bachelor of Education in Design and Technology and achieved the Qualified Teachers Status. From 2003 to 2005, I worked as a Supply Teacher in Caernarfon, Gwynedd.

8. In January 2006, I worked full time covering a teacher who was on maternity leave. From 2007 to July 2008, I worked part time whilst the teacher returned on a part time basis.

9. From September 2008 to approximately October 2010, I continued with supply work in a secondary school in Caernarfon. It was getting close to the summer holidays and due to the perceived risk of vCJD, causing me stress and difficulty coping, I was getting ill, suffering from nail separation and had regular visits to the GP. I finished work in October due to health issues.

10. I intend to speak about my diagnosis of Haemophilia C which was diagnosis was described as Factor X1 deficiency and my increased risk of variant Creutzfeldt Jakob Disease (vCJD) which has caused me trauma through the delays in receiving medical treatment and over the years. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, especially as later in life I found out the diagnosis of being a haemophilic, was incorrect.

11. Research by the Infected Blood Inquiry discovered a complaint I made to Kathy Jones, Complaints Manager at the health board. There were a series of letters:

12. 30th July 2009 from Dr Hamilton's Consultant Haematologist this letter explains how she has reviewed my case notes last paragraph 'you may request an independent review of your case notes if you are not happy with my explanations.'

13. I said yes then came the involvement of Kathy Jones, complaints manager. (Also the letter dated above was the first time I knew I had been tested for HIV Hep B /C)

14. I was given the telephone number for Kathy Jones (KJ) Complaints Manager. During the first phone call I asked her for an independent review of my medical notes. I was told 'We don't do them' she gave advice 'to ask the haematology manager to look at my notes and answer my complaints' she asked for my verbal permission to do this I was reassured this was the right way to move forward.

15. There were also further and letters during this period:

Date	From/ to method	Comment
26.1.10	Call JK to	Initial complaint telephone call
2.3.10	Letter from KJ	'I write further to our telephone conversation today' 'Whist issued raised occurred outside the time limits allowed for submitting a formal compliant within the NHS Complaints Procedure enquiries are still being instigated into the points you raised and we will contact you in the near future'
9.4.10	Letter from KJ	'Investigation into the concerns you raised still ongoing'
27.4.10	Letter from KJ	'Not in a position to respond to my complaint'

13.5.10	Letter from KJ	'Still not in a position to provide you with a full response to your complaint.'
24.5.10	Letter to KJ	Formal complaint made in writing Following a phone where told to make official complaint in writing.
22.6.10	Letter from JO	From Jane Ould (JO) Senior Secretariat Officer. 'the complaints department at Ysbyty Gwynedd Bangor have forward to me a copy of your letter dated 24th May 2010 requesting independent review ..'
28.6.10	Letter from JO	Thanking me for my signed consent for the release of personal information relating to my complaint.
27.8.10	Letter from JO	'we are still awaiting for the information, regarding your complaint from ....Ysbyty Gwynedd ..'
14.9.10	Letter from JO	Informing me that the information is being prepared.
23.9.10	Letter from JO	'Confirm we have the copies of the information'
29.9.10	Letter from	John G Ellis, Lay Reviewer for the independent review.
25.10.10	Letter from JO	'I confirm that we have requested an independent clinical report from a consultant Haematologist' Which led to the report dated 3rd December form Jane Ould
7.12.10	Letter from	John G Ellis lay reviewer …'you have the right to refer matter to the ombudsman for wales
	Phones call KJ	'I'm not happy' with what I read in report above have questions need answers…suggestion meeting with staff members - I agreed
2.2.11	Letter from KJ	'Thank you for agreeing to meet with staff members on 8th February" (this was meeting number 1), N.B. I have had 3 meetings in total)
8.2.11	Meeting	'I'm not happy with outcome of meeting'
3.3.11	Letter	from Mary Burrows (MB) Chief Executive
10.3.11	Letter	from Hayley Morgan thanking me for my telephone call to complain to the Ombudsman
14.3.11	Form	I filled out the form making my compliant to the Ombudsman
21.3.11	Letter	from Haley Morgan 'thank you for your complaint'
18.4.11	Letter	from Bernard Nolan, Ombudsman
1.06.11	Letter	from Bernard Nolan, Ombudsman
15.06.11	Letter	from Mary Burrows (MB) Chief Executive

16. In conclusion; even after all these letters and phone calls I was getting nowhere.

17. The complaint was regarding obstacles I encountered, whilst trying to seek treatment for a number of health conditions which had been withheld from me due to a perceived risk of vCJD within the NHS. Due to the strength of the vCJD prions, there is a risk of contamination on medical instruments.

18. It is my understanding that the National Health Service ("NHS") policy is that they have to be destroyed after use. This has caused problems for me in terms of operations either being delayed or cancelled, whilst trying to resolve these issues.

19. In 2010, I complained to the Health Board and underwent a process of an independent review of my medical file but for the purpose of this statement, I will refer to this document's heading "Clinical Advisors Report" (Exhibit **WITN4099002**). This review was completed on 3 December 2010 by Jane Ould, the Senior Secretariat Officer at the Independent Complaints Secretariat. Contained therein are chronological points of my medical history which I will refer to throughout this statement.

20. I have my medical records from St David's Hospital, Bangor and Llandudno General Hospital covering three years from 18 May 2012 to 17 February 2015. These have come into my possession because I instructed Slater and Gordon Solicitors, formerly Goodmans Law, to look into the possibility of medical negligence in 2012. On my behalf, they applied for my medical records, then later passed them onto me.

21. Following difficulties receiving proper information regarding two CT scans and the barium enema operation I went through, I decided to apply for my medical records covering the dates 31 January 2017 to 3 July 2017.

22. The medical records application process consisted of a phone call to the main desk of the hospital to ask how I could get my medical records. I was put through to the records department which is in Ysbyty Gwynedd. They sent me a simple two-page Access to Information form to fill in. I input the dates and explained what I wanted to see. They gave me what I wanted.

23. I am providing this witness statement because I believe that there has been a cover up. I will explain this with a full account of what has happened to me. I believe that the health board mixed up GRO-C and I as patients when it came to the treatment I received in the early 1990s.

24. In 1993, I was incorrectly diagnosed with Haemophilia C, a Factor XI Deficiency consequently, I received three Factor XI plasma injections as listed below:

Operation 1: On 28 February 1994 during a teeth removal procedure, I received Factor XI 890 IU (1 vial) (see **WITN4099002**) at Ysbyty Gwynedd Hospital - highlighted in Point 3 of the Clinical Advisors Report of Exhibit 2.

Operation 2: On 21 July 1994 during a termination of pregnancy, I received Factor XI Concentrate, 20mls at St David's Hospital - highlighted in Point 6 of the Clinical Advisors Report of Exhibit 2.

Operation 3: On 3 January 1995 during a gallbladder operation, I received 600 IU Factor XI Concentrate at Ysbyty Gwynedd Hospital - highlighted in Point 12 St David's Hospital.

25. I believe there was a cover up for three reasons:

(1) In 1993, I had no monitoring blood tests (in preparation for my teeth removal on 28 February 1994).

(2) When GRO-C by Dr Korn (attending physician) between 1992 and 1993, she was told she had a severe Factor XI deficiency. I was told in 1993 that I had the same bleeding disorder but to a lesser degree. We were told that plasma would be kept on standby for use during the teeth operation postoperatively if required. But, I was administered the plasma preoperatively. They did

not wait for a bleed. There was no discussion, no consent from my mother (I was a minor at the time). It is my belief they treated me as if I were GRO-C, with the more severe bleeding disorder.

(3) In July 1994, at the gynaecology procedure when I was aged 15 again I was not treated post-operatively as had been agreed, but pre-operatively; no bloods were taken beforehand. There was no discussion or consent obtained.

26. This leads me to believe that the hospital were treating me as though I had GRO-C and upon realisation, I think they have covered this up. I have no physical evidence, but it is my belief that this led to a cover up.

27. In addition to the cover up I describe above, I would also like to disclose the following. At a much later appointment, some 15 years after being diagnosed in 1993, I was informed by Dr Hamilton that my diagnosis of Factor XI Deficiency was wrong and in fact, I am not a Haemophilia C sufferer. This has had a profound effect on my life and over a 15 year period, I have been treated improperly. However, I will discuss this in my statement as it develops.

Section 2. How Infected

28. It all started when GRO-C, was diagnosed with haemophilia between 1992 and 1993. Following a hysterectomy GRO-C had unusual bruising afterwards. The hospital carried out some tests and informed her that she has Haemophilia C, a Factor XI deficiency. She requires no every day treatment but only requires Factor XI plasma injections during operations.

29. I was an active and healthy child. Apart from having gallstones in my teens, I maintained a normal body weight and was quite a happy child.

30. In order to make room for braces (when I was aged 15), I needed to have two molar teeth removed. My dentist, Dr David Roberts in Dental Surgery, 63 High Street in Bangor, Ysbyty Gwynedd thought that due to GRO-C, I should be tested for the same bleeding disorder. It would be safer to be tested before the procedure, in case I had a bleed. So, I was referred to Dr Korn in the haematology department of St David's hospital, Bangor (hospital no longer exists).

31. Dr Roberts wrote to the hospital requesting that I should be tested for the same blood clotting deficiency as my mother. Dr Roberts had also been liaising with Dr T R M Jones at SHO Oral Surgery. Dr Roberts was my dentist, who made the referral for braces.

32. The removal of the 2 molar teeth was to make room for the braces, Mum told Dr Roberts during the dentist appointment (when discussions took place that I needed to have teeth removed) GRO-C. By examining the Clinical Advisors Report (**WITN4099002** above), I worked it out to be somewhere between 9 March 1993 and October 1993 that Dr Korn carried out blood tests.

33. On 19 October 1993, when I was approaching 15 years old, the results came back for the Factor XI deficiency test and Dr Korn informed me. Mum was there with me for a diagnosis that I had a mild version of Factor XI deficiency (53%, borderline low on the Factor XI blood clotting test). I was a little frightened it was explained to me GRO-C GRO-C' words to the effect of as I recall Dr Korn explaining. GRO-C GRO-C we got through this together and just accepted it.

34. At the point of being informed, I must say I trusted St David's Hospital and their diagnosis. I recall going to the hospital to have two teeth removed. My mum did not sign any documents for consent, nor was any verbal consent given and there was no discussion of any risks involved.

35. Dr Korn, the Consultant Haematologist and Dr Rachel Williams, a staff grade doctor were involved in administering plasma to me, my teeth were removed. I had no bleeding problems either during or after the operation.

36. In July 1994, I had a gynaecological operation age 15 at St David's Hospital, Bangor. Prior to the surgery, they administered plasma to me again. There was no discussion of consent or the risks involved. This time I remember them trying to find a vein and then trying to get it in on the sides of my wrists. They tried one wrist then the other. It hurt. I still have the scars on my wrists where they put the needle in.

37. In December 1994, I attended the hospital for the first scheduled gallstones operation. The medical staff told me I had an infection but did not tell me what it was, nor provide me with any antibiotics. This first scheduled operation didn't go ahead because of the infection. I was sent home, I was aged 16.

38. Years later, upon examination of Point 8 of the Clinical Advisors Report, I discovered that, on 9 December 1994, it was noted that "Ms Lock should be inoculated against hepatitis A & B prior to surgery". From the independent review J Ould from the report 3rd Dec 2010 first time I learn of being 'inoculated'

39. I remember having to go back for further blood tests in December 1994 (I have a date of blood test done 09/12/94 so this must have been when they sent me home from the first scheduled gallbladder operation. (Point 11 of the Clinical Advisors Report). I never knew what they were for at the time, I was 16 years old and trusted the doctors so I did not question anything. Looking back at Point 13 of the Clinical Advisors Report, it looks like on 3 January 1995, I was confirmed not to have HAV, HBV, HCV and HIV.

40. Having discovered this information, I can categorically say that I was not asked for consent, nor was I informed of the results at the time. Upon reflection, this is worrying, I don't understand why they could not ask me or tell me.

41. On 3 January 1995 at 16 years old, I had a barium enema to diagnose gallstones and needed surgery under Dr Rachel Williams (as Dr Korn was away) at Ysbyty Gwynedd, a district general hospital in Bangor to remove the stones and the gallbladder itself. Again I was administered Factor XI plasma, without giving my consent. In a later conversation with my mother, she told me that there were no questions, no signed documents, there was no consent asked or given.

42. 1995 to 1998 I was studying for my A levels, (working weekends in a local Tesco store) at school. In September 1998 started a BA Hons (Art and Psychology) at Chester University. I left in January 1999 as I was pregnant with my son and wanted to moved back home.

43. Had my son in GRO-C 1999, he was born by C-Section, weeks later I was very unwell after had to be re admitted to hospital for another operation under general aesthetic, I had a D and C because I had an infection.

44. I was slightly under weight suffered from palpitations and treated with propranolol. August 2000 went into hospital for pneumonia, I recall a stay for a number of days with this, because my body weight was low.

45. In September 2000 I started my BA Ed. in Design, Technology and Art in Bangor. I graduated in 2003.

46. In approximately January 2003, my mum received a telephone call from the hospital GRO-C The Haematology Department requested tha GRO-C her children have some blood tests in relation to Factor XI.

47. Mum has told me she does not know or recall the name of the person, who made the call that lead to the genetic testing, they told my mum it was for research purposes. Without doubt she recalls it was for the purpose of research. Shortly after the initial call, my mum took myself GRO-C

GRO-C for these blood tests. We gave our blood and that was it, no follow up, nothing.

48. Again in 2003 after the tests, I had no choice but to trust the medical professionals for my appropriate healthcare treatment. This related to hospital's in general, I recall and mum recalls bloods were taken at Ysbyty Gwynedd hospital I didn't give it much thought I carried on believing that I was a haemophiliac. I had no reason to think otherwise.

49. In a letter (medical files disclosed from Slater & Gordon) dated 13 February 2003, Roger Mountford, Head of the Merseyside and Cheshire Regional Molecular Genetics Laboratory, Liverpool wrote to Dr Paula Bolton-Maggs, Consultant Paediatric Haematologist at Alder Hey Children's Hospital about GRO-C and I's diagnoses (Exhibit **WITN4099003**). The letter reads:

*"**Report to:***
Dr Paula Bolton-Maggs
Consultant Paediatric Haematologist
Alder Hey Children's Hospital
Eaton Rd
Liverpool L12 2AP

Patients Name	*C128X RESULTS*
GRO-C *(dob* GRO-C*81)*	*n/n*
GRO-C *(dob* GRO-C*81)*	*n/n*
Julie Elizabeth Lock *(*GRO-C*78)*	*n/n*

Key n = normal   M = mutation present

The above patents have a family history of Factor XI deficiency GRO-C

GRO-C

GRO-C

The above patients have been shown to be negative for this mutation using an MS-PCR based assay.

This does not exclude a diagnosis of Factor XI deficiency as it is not clear whether GRO-C *has a second unidentified mutation in the Factor XI gene.*

Signed:	*Checked:*
Roger Mountford - Head of Laboratory	*Clinical Scientist"*

50. At Point 27 of the Clinical Advisors Report, it is stated that *"c2003-4: genetic testing shows that Ms Lock* GRO-C *do not carry the C128X mutation in the factor XI gene that was detected* GRO-C

GRO-C

51. In a letter dated 5 June 2003, Dr Paula Bolton-Maggs, Consultant Haematologist wrote to Dr Maria H Gilleece, Consultant Haematologist at North West Wales NHS Trust, Ysbyty Gwynedd, Bangor informing of the genetic analyses of my brothers and I (Exhibit **WITN4099004**). The letter reads:

"Case Number: GRO-C
Date: 05 June 2003

Dr M H Gilleece
Consultant Haematologist
North West Wales NHS Trust
Ysbyty Gwynedd

Bangor
Gwynedd LL57 2PW

Dear Maria

Re: Mrs GRO-C ***DOB*** GRO-C ***1952*** *-* GRO-C *- F*
GRO-C ***DOB*** GRO-C ***1981 -*** GRO-C *- F - XI : 74.9% (Jan 03)*
DOB GRO-C ***/1981 -*** GRO-C *- F - V2 - XI = 77% (Jan 03)*
Julie E Locke DOB GRO-C ***1978 -*** GRO-C *- F - VZ - XI = 67.6% (Jan 03)*

I enclose the genetic analysis of the GRO-C*. As you see, none of them have the got the C128X mutation. I would be grateful if you could confirm what there factor XI coagulation levels are. These results certainly suggest that they should be normal unless* GRO-C *has an additional mutation for factor XI deficiency.*

Many thanks
Yours sincerely

Dr P Bolton-Maggs
Consultant Haematologist"

52. In 2003, this is what the hospital knew at this particular juncture in time, however I was unaware, until I had the meeting with Dr Hamilton on 8 June 2009, some six years later.

53. Life dramatically changed for me in February 2009 when I received two letters. Letter one dated 17 February 2009 appears to be a generic lookback letter (Exhibit **WITN4099005**).

"Dear Sir/Madam,

Re:- Information about variant CJD

We have been asked to send out information regarding variant CJD. There is a theoretical risk that patients who have received plasma products between

1980 and 2001 are at increased risk of variant CJD. For all of the patients with bleeding disorders registered at Bangor, you were contacted in 2004 regarding your personal risk. For the vast majority of our patients the information does not apply directly to you and I wanted to reassure you of this.

In particular the leaflets enclosed contain a lot of information which may not be relevant. If you need to discuss this further or have any concerns please contact us at the haemophilia centre.

Yours Faithfully
Dr. M. Hamilton,
Consultant Haematologist."

54. Having read this letter, there is reference to a 2004 letter. Please note, my mum has the same initials and address as me.

55. After speaking with my mum, she confirmed that there was a 2004 letter. GRO-C I did not receive the 2004 letter. GRO-C GRO-C

56. Letter two dated 18 February 2009 (Exhibit **WITN4099006**) reads as follows:

"Dear Ms. Lock,

Variant Creutzfeldt-Jakob Disease (vCJD) and patients with bleeding disorders who have been treated with UK plasma products

We are writing to all our patients with bleeding disorders to tell them about a person with haemophilia who has been found to have evidence of the infection that causes variant Creutzfeldt-Jakob Disease (vCJD) in his spleen at post mortem. All Haemophilia Centres are contacting their patients throughout the UK to give them this information.

Tests carried out on a haemophilia patient who died last year have shown that he was infected with the abnormal prion protein that causes variant Creutzfeldt-Jakob Disease (vCJD). The patient did not die of vCJD, and never had any symptoms of this disease when he was alive. The patient was in his 70s when he died of a completely unrelated cause. The tests were carried out as part of a research study jointly co-ordinated by the UK Haemophilia Centre Doctors Organisation and the National CJD Surveillance Unit.
Yours sincerely
Dr M Hamilton
Consultant Haematologist
Sister Nerys Bale
***Haemophilia Specialist Nurse**"*

The remainder of the letter can read in full at **the above exhibit number**.

57. I and my parents learnt that in fact, I could possibly have been infected with vCJD when I received blood plasma for a Factor XI blood clotting deficiency that, as it turns out, I don't even have. This letter was actually the start to me finding out the truth that in fact I am NOT a haemophiliac, I do NOT have this bleeding disorder.

58. This terrifying brain wasting disease for which there is no cure frightened me. I became ill with fear and confused to learn that actually, I didn't have Factor XI deficiency, therefore I should not have received the plasma product in the first place. I do not have the faulty gene. The frightening letter prompted me to question everything.

59. I was angry, shocked and confused to learn that I'd been put at risk of a horrifying disease as a result of treatment, I didn't even need. This filled me will dread. A nightmare panic. I can't enjoy life anymore with random thoughts about having and dying of vCJD.

60. It's always there in my mind. I feel on edge, if I get a little muscle twitch and I'd think I've got vCJD. It's a massive cloud over me with the added stress of fighting for medical diagnosis and treatment. (From 2011 to 2017 it took that length of time to find out my ovary was stuck to my abdominal wall!).

61. My health has deteriorated since this original letter. I believe the stress has caused my arthritis. I suffer infections regularly. I sufferer with reoccurring shingles, I have had shingles at least 10 times especially over last few years.

62. More recently 21st July 2021 went to A and E and was diagnosed with Cellulitis in my right thigh. I had to be admitted because the infection was so bad to receive IV antibiotics. My Immune system is not great. Stress defiantly affects it.

63. A couple of weeks before this I recall my abdominal pain was horrendous I went to A and E and needed help. I was asked if I knew I had adhesions. I told her yes. She said it's probably that. My abdomen was so distended she wanted to do a pregnancy test (no help whatsoever). I told her the test would be a waste of time I'm not pregnant, she asked if I was refusing to take the test I walked out, came home and cried.

64. I recall speaking with Dr Stuart the next day telling him I feel like I'm dying; the pain is horrendous. I asked for antibiotics, I felt that they would help and thank goodness he gave me them they helped with my pain. I must have had some infection. Then about 2 weeks later back in A and E diagnosed Cellulitis right leg.

65. I did explain to the doctors that I had attended recently with sever abdominal pain, I thought it was odd that it was my right leg, in case there was a connection. Right side of my body again. (diverticular bowel right side/ovary adhered right side) They did listen, and assured me that in any event even if it started on you right side anywhere in the abdomen IV antibiotics would be the way forward.

66. On 3 June 2009, I received a letter of what appears to be a generically designed information letter but was actually signed by Dr Hamilton (Exhibit

WITN4099007). However, of note on this letter, are two things which I would like to draw the attention of the Inquiry to.

*"**This new information does not change the way you will be treated.** As you have a bleeding disorder or congenital antithrombin III deficiency and have received clotting factors or antithrombin made from UK-sourced plasma between 1980 and 2001, you are considered to have an increased risk of vCJD for public health purposes, and you should follow public health advice (see box)."*

67. Directly below the above, there is a box headed 'Advice on how to reduce the risk of spreading CJD to other people'. The third and fourth bullet point read: *" • If you are going to have any medical or surgical procedures, you should tell whoever is treating you beforehand about your risk of vCJD so that they can make special arrangements for the instruments used to treat you*

• You are advised to tell your family about your increased risk. Your family can tell the people who are treating you about your risk of CJD if you need medical or surgical procedures in the future and are unable to tell them yourself."

The remainder of the letter can read in full at **WITN4099008**.

68. I felt like I was some kind of biohazard. I thought if I die, do I have to be cremated or buried in a special bag? Again, I had thoughts of dying. Could I pass this on? Thoughts overload. Going to the trouble of reading all these surgical rules that they had to follow when looking at me makes me think gosh I must have vCJD. I had depressing, morbid thoughts, and I still do.

69. I received an awful letter about how I was advised to tell everyone of my risk of vCJD, further leading into the mindset that I was a biohazard. As well as conversation about how to reduce spreading vCJD to other people, and that lead to me having horrible social anxiety, where I was afraid to associate myself with others, or be around them, for fear of spreading this horrible disease, especially to my loved ones. It affected many of my relationships with my family and others.

70. I was working at this time as a secondary school supply teacher, and I actually thought; What if the parents of the children I taught, found out. Is it right? Should I be working with children? Can I spread it? I actually felt guilt going to work especially as it was with children. I wondered how I would feel if my son had a teacher who could have vCJD that could spread. I'd be uncomfortable with that! The unknown? It was surreal. Awful. I remember it playing on my mind whist at work also. The thought that I could have vCJD, it has ruined my enjoyment of life. I'm spending most of my time worried about something I may or may not have its just awful.

71. I was told nothing before February 2009, apart from reading the words 'at risk of vCJD' 'monitored for vCJD' 'possible vCJD' and lastly 'vCJD Status' written all over my hospital case notes.

72. The letter of 17 February 2009 is written to Sir/Madam and the letter of 18 February 2009 was written to Ms J E Lock. GRO-C I received Factor XI blood plasma, and GRO-C given the same diagnosis, we were confused that only one letter had been sent about the warning of vCJD. I phoned the haematology department to find out if the letter was for myself or GRO-C.

73. On the telephone call, they listened to my concerns and invited GRO-C GRO-C for a review at Ysbyty Gwynedd, Bangor within a matter of weeks from receiving the letter. They said that haemophiliacs are usually reviewed annually, but GRO-C I had not had a review in years, likely since 1999 when my son was born.

74. On 8 June 2009, I had an outpatient appointment with Dr Hamilton. She suggested in a letter from her on 30th July, it reads 'diagnosis:? Factor X1 deficiency', that I may not have a Factor XI bleeding disorder as my blood test results were normal.

75. In 2010, when I had a review of my medical file, I found out that the blood tests were actually genetic testing for Factor XI deficiency. I found out that I was negative GRO-C clotting levels were normal. GRO-C did not have this mutation. GRO-C GRO-C. So finally, several years later I found out the results of the blood test in 2003.

76. In hindsight maybe the person who received the genetic testing results, who obviously physically put the letter into my case notes. Logically I believe that the nature of the letter should have been for the concern of the haematology dept. It is my belief they put it into my medical file and didn't inform the Haematology department.

77. Not one person from the haematology department phoned to give us the results. I had continued to believe that I had a bleeding disorder. They had an opportunity to let me know that actually I wasn't a haemophiliac, but they didn't. They chose not to, shame on them.

Section 3. Other Infections

78. At the beginning of December 2010, I found out that during the blood tests for my gallbladder, what they were actually doing was testing me for Hepatitis A, Hepatitis B, Hepatitis C and HIV according to Point 8 of the Clinical Advisors Report. At the time I had no Idea. The only thing I recall is that they said I had an infection. I only found out that I had been tested for these infections 15 years later because I had undergone this complaints process.

79. I was shocked, disturbed and terrified. I never received any information about these infections, hepatitis or HIV. I also started to worry about other viruses. I became paranoid thinking *"what else could I have possibly contracted?"* I would feel confused, I just didn't understand it.

80. Apparently, I was inoculated against Hepatitis A and Hepatitis B in December 1994, Point 11 of the Clinical Advisors Report) I can honestly say I have no recollection of this.

Section 4. Consent

81. As mentioned above, I was given plasma and tested on three occasions without consent. I was also tested for Hepatitis A, Hepatitis B, Hepatitis C and HIV, no consent was given. There was no paper consent for the 2003 genetic blood tests. Mum was not told about genetic test just tests for 'research', she agreed verbally on the phone and took us for blood tests

82. No discussion took place about the Hepatitis A, Hepatitis B, Hepatitis C and HIV tests or why they were doing these tests, but I didn't question them. I had faith that the hospital would make the most appropriate decisions for me. My mum was also not aware of any testing for the above or immunisations I had conversations with mum about this. No consent was given. There was also no mention of HIV Hep A, B, C I believe this does shed light on the fact that there was a cover up.

83. I can confirm that I was not provided with adequate information around managing the Factor XI deficiency. I was not provided with sufficient or timely information correcting that diagnosis and I now have not been provided sufficient information with how to cope with the potential of vCJD.

Section 5. Impact

84. In 1981, my younger twin brothers were born GRO-C GRO-C

85. In 1999, my son was born at Ysbyty Gwynedd, under Dr Seale, Haematologist. It was explained to me by Dr Seale that I had to have a Caesarean section ("C section") due to my Factor XI deficiency. An epidural was not an option as it was unsafe, so general anaesthetic was the best option for me. I agreed.

86. I wasn't awake when my son was born. The first time I saw him was in a photograph brought to my bed as I was waking up from the general anaesthetic. The wrong diagnosis of Factor XI blood clotting deficiency determined how I had my son and put me at an unnecessary risk.

87. Finding out years later that I don't actually have Factor XI deficiency makes me question that I actually could have had an epidural and been awake when he was born.

88. I rationalised the C section procedure by thinking the doctor at the time made the best decision, based on the diagnosis that was on my medical file. As it was an emergency C section, his decision was one to keep my baby and I safe.

89. However, in hindsight, giving birth to your children is one of the most joyous occasions that a human can have. The fact that I underwent an unnecessary procedure has soured that memory.

Physical/Mental effects

90. As a consequence of my vCJD 'status', I suffered from anxiety and I worried about becoming unwell. It affected me mentally and I became physically ill. I developed psoriasis, arthritis and suffered from nail separation from my nail beds.

91. In 2010, Dr Yasmeen Ahmad, a Consultant Rheumatologist at Ysbyty Gwynedd Hospital and Llandudno General Hospital put me on two types of immunosuppressants - Methotrexate 20mg once a week and Sulphasalazine 3g daily.

92. I had been referred 25th March 2010 by Dr L Kraaijeveld referred me to Rheumatology. She wonders if I have psoriatic Arthritis (nail involvement separation on the nail beds, joint pain in hands with swelling) Dr Yasmeen Ahmad (Llandudno General Hospital) wrote back to GP DR L Miles saying she probably does have Psoriatic Arthritis

93. I was having blood tests every two weeks, having been diagnosed with psoriatic Arthritis, the treatment for which is immune-suppressants, they needed to monitor blood in case infections occur. Blood monitoring tests were done in my GP surgery started 7th Sept 2010 every 2 weeks then from 18th January 2011 every month up until approx. 2015.

94. I believe the shock and stress caused me to develop this condition. I attribute my decline in health due to the vCJD risk category that I have been placed in. The stress caused by also trying to get answers to my questions, my concerns.

95. I have also developed Hashimoto's thyroid disease (an autoimmune disorder causing the immune system to attack the thyroid, limiting the production of thyroid hormones which in turn, affects every organ and slows down the body's functions).

96. I've had battles in my head, overthinking everything and realising that I'd been put at risk of a brain wasting disease for nothing. If I was a haemophiliac I could possibly justify that the plasma saved my life, but I can't. The truth is that the doctors put me at risk, potentially of blood clots, they could have killed me.

97. I read the words viral 'surveillance' blood tests and ask myself if they are watching and waiting to say *"Is it vCJD?"*. The NCJDRSU, Prion Unit maintain that there is no accurate blood test for it. I only know about the Prion Unit because of Goodmans Law

98. I have no trust in the health board whatsoever now. I even considered whether I was an experiment into bloodborne disease or something else.

99. This ill health has detrimentally affected me for the rest of my life, my life is ruined.

vCJD List/ Prion Unit

100. Even though GRO-C and I both had plasma, only I am on the vCJD list. I know this because I have received letters (GRO-C was given plasma for X1 deficiency also, same disorder) GRO-C has not received any letters and is not at risk of CJD, so clearly they are not sent out to all bleeding disorder suffers, therefore it follows; they have decided who is at risk and who is not. They must have list of those 'at risk' otherwise everyone would get these letters, for public health purposes.

101. To date, I have not had a logical explanation from the doctors, regarding why I am on this list GRO-C Given the lack of clarity provided, it makes me wonder GRO-C whether her treatment is right?

102. In light of finding out that I am not a haemophiliac, but was put at risk of vCJD for no reason, I enlisted the help of Ruth Thomas, Senior Caseworker at Goodmans Law, (now known as Slater and Gordon) 4-6 St John's Road, Liverpool. Their involvement was beneficial to some degree. Through Slater and Gordon, I learnt about the Medical Research Council - Prion Unit ("Prion Unit") in London that could possibly carry out diagnostic tests to determine if I have vCJD or not.

103. In 2015, I took litigation for negligence against NHS Wales, the outcome was £17,500.00 in my favour (this helped with cost of living over following 3 years as I was on very low income). They admitted it was negligent to give treatment of the plasma. This was out of court settlement.

104. 14TH May 2015 'NHS Wales Legal and Risk Services' letter of settlement confirmation the letter states: 'that Miss Lock is concerned as to whether her status is impacting upon her current treatment by the Health Board. We are aware Miss Lock has raised a concern regarding this with the Health Board and that is being Investigated' .....'We shall notify the Health Board that matters need to be expedited and a response given to Miss Lock as to the position regarding her current treatment.'

105. This didn't happen is was not until 03 July 2017, after I got Sain Gwenllian AM member got involved. If I had not of asked for her help I'm confident to say I would not have had the diagnosis of Adhesions. I don't know what happened here with DR Hamilton and Dr Klazinger both leaving the hospital at this time.

106. On 11 July 2012, I received a letter from Professor John Collinge, Professor of Neurology at the Prion Unit and believed that this would be a positive way forward. They were happy to meet with me. But there were no further tests, they explained the tests they do have, were not suitable for someone like me

107. I had to go through hoops to get an appointment with The Prion Unit. Goodmans Law told me about the Prion Unit suggesting it may help to see if there was evidence of vCJD. In 2013 they wrote to the unit but were told they 'cannot accept private referrals'. I have letter dated 24th June 2013 from Goodman Law. 'Your GP cannot refer you through the NHS as you live in Wales' '...we have spoken to your GP surgery this morning and they have indicated way round it'...'go back to the hospital to see the haematologist for the referral to be done'.

108. The Prion Unit could not accept my GP referral, nor a self-referral. In the end, I had to go back to the Haematology Department and ask Dr Hamilton if she would kindly refer me. I recall they were reluctant to do so but they did. This was difficult, I felt worthless because I had to ask and justify why I wanted the referral.

109. I finally managed to get an appointment with the specialist in London, the Prion Unit. On 24 August 2013, I travelled 5 hours by train. I saw Dr Simon Mead, Consultant Neurologist who explained to me that the test they actually have is not reliable in a patient like me.

110. In a letter from Dr Simon Meade to Dr Hamilton, dated 25 September 2013 (Exhibit **WITN4099009**), it is stated that *"Julie expressed a wish to have a blood test to find out whether she is infected. We had some discussion about this and I explained that we do not feel that, at present, our test is accurate enough to justify testing people like her. This is because the true risk of her being infected is very, very low and we still require more information about whether our test results in false positives."* Dr Mead said it may give an inconclusive result. He did not wish to put a *"cloud over me"*. I explained I already had a cloud over me. He refused to carry out any test.

111. In the original letters, it is clear that they were eager to help, but their attitude somewhat changed towards me after the involvement of my haematologist, Dr Hamilton who referred me:
Letter dated 13 August 2013 Diagnosis:
1) Mild Factor X1 deficiency
2) Treated with plasma products in 1994 and 1995, therefore considered at risk of vCJD for public purposes
Letter dated 8th August 2012 from Peter, Prion Unit to Goodmans LAW outlining possible tests I couldn't understand why the Prion Unit would go from suggesting a number of tests to actually doing nothing. Telling me a blood test is not suitable I could have a false positive.

112. The only test they did was make me walk in a straight line and checked my balance. I had gone down to London, from Wales just to walk in a line. I couldn't get my head round it. There was no value in this whatsoever.

Work/financial

113. I remember trying to work at the beginning of the new term in September 2010 but I had awful nail separation from my nail beds and extremely painful joints, mainly in my hands. It started suddenly and I couldn't cope working, though I did try.

114. Around 2012, I gave up work as a Supply Teacher. I developed a severe abdominal pain and being told I could have vCJD was a strong factor in my decision to give up work. I wasn't able to have any surgical procedures due to the risk of vCJD and so, my abdominal pain could not be diagnosed or treated. On this basis, I was denied surgery.

115. The question of vCJD and the severe abdominal pain made it impossible for me to carry on working. In late November 2010, I made a claim for Employers and Support Allowance ("ESA"). I visited the GP, they wrote me a sick note and I would forward it to DWP to inform them that I was unfit for walk; a medical assessment would follow.

116. In 2011, I was getting a basic amount of £74.00 per week for the next few months, then I later had a medical assessment at a local medical centre to assess my illnesses. At the time, they operated a points system. I was asked questions about my physical mobility such as how far I would walk unaided.

117. I remember thinking that *"I am not claiming any disability benefits, I am claiming that I was too sick to work"*. This lasted for 20 minutes. It was a demeaning process. I question whether the person who carried out the assessment had any medical training or knowledge.

118. I was awarded zero points on a sliding scale of zero to 15 points. This was despite my arthritis and Hashimoto's disease. I was struggling with abdominal pain, which made me feel very depressed and stressed. The hassle of applying for benefits, general feeling of wasting my time. Knowing that I have conditions that other people get ESA for, I was very stressed, tired and anxious, it was unbelievable.

119. During this assessment, I couldn't tell them what was wrong with my abdomen because I didn't know. The vCJD status prevented me from getting treatment, obtaining a diagnosis and therefore, giving an explanation to the assessor. As a consequence of achieving zero points, they stopped my claim.

120. I went to the jobcentre, I don't think they thought it was right either. I was informed that I could make a new claim for a different condition, so I did. I had lots of things going on and my Hashimoto's thyroid disease was another thing. I went back onto the ESA with a different condition, all on that flat rate of £72.00 - £74.00 a week.

121. Then, after several months I was required to attend another medical assessment. The outcome of the second assessment resulted in me being awarded zero points again. I subsequently appealed over the next few months. I then made an appeal against their decision and this was declined. I was so frustrated by the assessment and appeals process that I made a formal appeal which was heard in Caernarfon Court.

122. On 4 June 2013, I attended Caernarfon Court to appeal the decision (with my Mum). I explained everything about my abdominal pain, vCJD risk on my file, thyroid disease, diverticulitis bowel disease and Psoriatic Arthritis. I can recall the date because mum has kept a calendar she would write all appointments on.

123. I remember the Judge slapped me down over the vCJD aspect; he asked whether I had vCJD or not. I went on to explain that I am at risk. He said he couldn't give points for something I don't know I have. I felt humiliated. I remember him making a comment about the fact I walked up the stairs in the court. I remember thinking I'm claiming a sickness benefit, not disability benefit.

124. He said *"we cannot decide an award for ESA because we don't know if you have it"* (vCJD). In hindsight he treated me like I made my health issues up. I actually had a sick note from the GP covering the court date and overlapping my claim for job seekers, the DWP and the court totally ignored it.

125. ESA was refused and they said I was fit to work. I have checked with local job centre, re the ESA; they tell me they don't have nots that far back available to them. After my experience with ESA and the whole assessment process being an absolute joke, I would never ever go through that again, it upset me that much that I'd rather starve than put myself through that process again.

126. The system ground me down and I gave up. On 11 June 2013, I visited the job centre and had to go on Jobseeker's Allowance ("JSA") with regular back to work appointments. I was in such horrific pain, I became very distressed each time I walked in and I felt so low. Not having much money pressure to pay bills. Limited had to survive on a minimal amount.

127. I stopped having haircuts and didn't buy clothes. My mum/dad would help out especially with clothing for my son I feel shame I needed their help. I didn't have a phone line as I couldn't afford it and had to use my parent's landline. Obviously, no holidays. It was basically food and bills. Could not afford a car or to even run one.

128. I felt sick, stressed and extremely anxious. JSA was my only option, otherwise I would simply have no money. I even had to go through all my medical problems all again during that appointment matching my suitability for work. I could describe it as a totally unbelievable experience.

129. I should never have been forced into that but I was. It was even suggested to me by a person in the DWP that I could possibly get income support but would need to take a reduced rate, if I felt I still was not able to work.

130. This experience left me suicidal (as previously mentioned). I lost everything, my job, my social life and I had no income. I was in hell. I became very isolated and depressed and even now, remain suicidal. I have letters showing I applied for PIP benefit on the 28/06/2020 was refused.

131. I started to think, if I do have vCJD what would be the most painless way of suicide? I would think about the most painless way to die overdose, jumping off Menai Bridge just stupid thoughts that I never thought of before the vCJD letter were sent to me.

132. It's hard to admit I had these thoughts because I don't want to be labelled 'mad'. I don't want to be looked after I don't want to die like that losing brain functions over days, months of suffering I'd want to die quickly I had never actually thought about how I was going to die until the vCJD letters, then suddenly 'I'm thinking about death and how will I die. That's the effect of those horrible letters that were sent to me.

133. Seeing vCJD on my medical notes makes it real. I say to myself this is really happening, 'oh my god'. I think about being a child in the 90s when it was reported on the news 'Mad Cow disease' and images off cows falling over in pain. It actually put me off eating beef when I was about 14. I still don't. I am on prescribed Iron, I know red meets are high in iron, I briefly considered eating beef but then got really paranoid thinking 'what if the beef I eat triggers my vCJD. I get silly thoughts. I have a phobia or even touching beef now never mind eating it.

134. I didn't want my family to have to care for me if this brain wasting disease took hold of me. I would think about how GRO-C ; I couldn't let them see me like that. But then, I'd look to my son and remind myself how much he needs me.

135. My thoughts could I have given my son vCJD, what does this mean for him? I have received the Plasma before he was born it was already in me. I shake when I give this thought. But thoughts are random and sometimes I cannot not think of it. I can honestly state I think about having vCJD every single day.

136. As I'm getting older and understanding it can take 40 year or so to develop I think, 'are the symptoms going to start'. If I forget something I think it's my brain… vCJD. It doesn't help having and underactive thyroid as I can get days where I'm so tired I get 'Brain Fog'. The letters have put the fear of god into me. I never had any more children.

137. Since 2014, I have been in receipt of a carer's allowance for GRO-C GRO-C I share care with my mum and other brother Andrew. This is very challenging especially with my ongoing medical problems but we don't have a choice. I receive £66.15 Carers Allowance with £42.95 Income Support. This totals £109 per week - that's what I have to live on.

Complaints Process

138. I wrote letters of complaint to the health board. Part of this complaints process led to a review of my medical file to help establish the truth. This went on for a few years. It consumed me.

139. Letter from Mary Burrows, Chief Executive to Julia Lock answering three questions regarding Julia's complaints of the health board dated 15 June 2011 (Exhibit **WITN4099010**). Mary Burrows answered three questions raised by me relating to the accuracy of the Factor XI deficiency test; whether my mother and I had been mixed up in 1994; and whether the hospital would have had stock of the plasma had her mother not been diagnosed with the Factor XI deficiency. At the end of her letter she wrote "*If you still remain unhappy you may wish to refer the matter to the Ombudsman, who can be contacted by telephone...*" I was not satisfied and I did take the referral to the ombudsman.

140. In 2013 after seeing Dr Klazinga privately and him suggesting Laparoscopy surgery to diagnose my pain. Then as an NHS patient it was not suitable for surgery due to vCJD 'note in evidence' he was of the opinion I possibly had endometriosis (very similar symptoms to what I actually have with adhesions)

I was offered a treatment of hormone injections I'm in so much pain I would have tried anything. I agreed to treatment plan.

141. These injections helped a little I was better with them than without for sure, but still experienced some pain. The injections are not used long term and was advised by Dr L Kraaijeveld my GP at the time to have a break from them. Pain returned to a level again that it was making life very difficult I now most defiantly needed the Laparoscopy surgery the pain was so bad I thought (convinced) I had cancer like my late grandmother. I was desperate. Could not cope with the pain.

142. I received numerous letters about my complaint about delays with my surgical procedures but these were reasons why it couldn't be dealt with. This are listed above.

Section 6. Treatment/Care/Support

Refusal of treatment due to 'vCJD' status

143. In 1994, I had a barium enema to diagnose gallstones which did not show any diverticula. If my notes were read or a follow up appointment had been made following this diagnosis, I could have explained that I did not have this before. The evidence showed that something happened to the right side of my colon, which coincides with my symptoms.

144. After having the barium, it revealed I had a duodenal reflux I was then sent for an ultrasound scan which showed I had gallstones that were causing my horrific pain. Then after the Laparoscopic Cholecystectomy (gallbladder with stones removal) in January 1995 I suffered with bleeding. Eventually I had a barium of the bowel this didn't show a diverticular bowel, so I didn't have it then.

145. I have a letter written by Mr Lloyd Jenkinson Consultant Surgeon , cc Dr KORN Haematologist with 'no date' stating 'we will consider barium studies…" I do recall having this done but my GP surgery have no notes with the results.

146. I received a letter explaining the results but I was never given a follow up appointment. I believe that they didn't give me a follow up because surgery was not an option, due to the risk of vCJD. I was left in pain. I had to revisit my GP.

147. I was treated for an infection due to diverticulosis and the antibiotics worked really well and reduced the pain. I had several bouts and antibiotics helped with the pain. I think they would rather think that I was born with the bowel problem, rather than believe there was something actually going on. This way, they could fob me off and avoid any procedure to help me. I was so upset about not having a follow up and felt abandoned in pain.

148. In 2012, I started to have abdominal problems. I visited my GP and informed her that I was suffering from pain on my right side. It was difficult to know if it was a bowel or gynaecological problem as the areas overlap. My GP referred me to a gynaecologist and suggested that a camera through the large bowel would help in the diagnosis of my pain.

149. My GP Dr Nina Cakiroglu on 27/09/2011 because of abdominal pain and bleeding made a referral to consultant of Colorectal and Laparoscopic Surgeon with the view to getting a Laparoscopy (a look at the bowels with a camera), This was in Llandudno General hospital.

150. On 13th April 2012 I arrived at my outpatient appointment at Llandudno General Hospital for the endoscopy of my bowel. The first thing Peter Roberts, the Colorectal Nurse Practitioner said to me was *"I can't do the test I'm afraid, but I will try to think about what else we can do"*. I tried to ask if this was because of the vCJD status on my medical file but he was very matter of fact and just repeated *"I can't do the test, it's not suitable, and those are the rules."* It was clear that the vCJD status prevented me from having any surgical examination due to the risk of possibly contaminating the equipment.

151. I attended Peter Roberts Clinic 18th May 2012 Decision to send me for an ultrasound. I also attended Peter Roberts Clinic 21st Sept 2012 and was told the ultrasound was normal. He decides to send me for the barium enema.

152. In a letter of 5TH OCT 2012 Peter Roberts writes to my GP Dr. Miles…'she complains bitterly of lower abdominal pain and she is convinced something serious is going on.' ….'we will see her in the outpatient clinic with the result from that' I was not seen again in clinic no follow up just a letter. His choice of words here upset me I kept telling him I was in abdominal pain.

153. In the end I was proved right to complain bitterly, I was in agony and my ovary was stuck to my abdominal wall and other areas of adhesions within the abdominal area sticking my organs together (3rd July 2017). Again I believe the delay here over some months before knowing I had diverticular bowel… was due to my vCJD on notes.

154. I was sent for my second barium meal. I have a letter dated 12TH Dec 2012 from Peter Roberts's Colorectal Nurse Practitioner "I am writing to let you know the results of the Barium Enema which you underwent recently. I am very pleased to say that it ruled out any sinister disease such as bowel cancer. You do however have Diverticulosis on the right side of the colon. This is generally a condition which is managed by good fibre intake. I have enclosed a leaflet on the condition and have discharged you back to the care of your GP'.

155. This was very distressing, I was in horrendous pain and certainly didn't think extra fibre would help. Again, I was discharged to my GP with no treatment? No opportunity to speak with anyone just a leaflet "information about diverticular disease." I'm thinking "I need help with my pain not a leaflet!"

156. In 20, I had my gynaecology outpatient appointment. They diagnosed a cyst on my right ovary and a cyst in my womb. I came up against the same attitude that surgery wasn't an option.

157. The Gyni staff played down the severity of the cysts. When I raised the question about whether there was a connection between the diverticula on the right side of the bowel and the right ovarian cyst, they agreed that there was a possible connection; right sided diverticula are not common and usually affect the left side.

158. They did nothing; offered no solution; no further investigations. I'm still in a considerable amount of pain on the right side. I left the appointment and cried. Then, after much thought about how I could get a proper diagnosis, and once and for all get rid of this awful pain, I decided to go private.

159. With very little money, I decided I had to pay for a private gynaecology opinion and diagnosis at Spire Abergele Consulting Rooms, Abergele, the date of this referral is 7th Feb 2013 by Dr Farrar my GP surgery with Dr D Klazinga, Consultant Gynaecologist. I had an invoice for £144, I had to borrow the money. This was embarrassing.

160. On 26 February 2013, I attended the appointment as a patient with no notes. The attitude from this particular consultant was very different. He Dr Klazinga told me what I assumed would be the right way forward; he confirmed that I needed exploratory surgery to get a proper diagnosis, and that this is the only way to determine the source of pain. I told him that it was exactly what I was thinking and then I explained what had happened at my NHS outpatient appointment. I told him about the vCJD.

161. He went on to explain that they do surgery on patients with hepatitis and other infections all the time so this shouldn't be an issue in his opinion. He helped me, he said I shouldn't have to pay for private Laparoscopy in his opinion He suggested that I have a follow up appointment with him as an NHS patient, as he also worked for the same Trust.

162. He saw me as an NHS patient on 06 Sept 2013 Dr B Jones GP referred me back to Gynaecology she explains 'abdominal pelvic pain...... scan has confirmed the presence of a Nabothian Cyst present since a previous scan some years ago' . But, he became blocked, he couldn't do the surgery he said I needed. In his privet clinic he was happy and suggested Laparoscopy to get the correct diagnosis of my abdominal pain. Then saw me as an NHS and he couldn't do the Laparoscopy is was not an option. 'not suitable for surgery due to vCJD' medical notes

163. He had a theory based on my symptoms that I could possibly have endometriosis. He arranged a CT scan, but was still of the opinion I needed surgery. He liaised with the Haematologist Dr Hamilton and Dr Klazinga, who gave their reassurances that they supported the surgery.

164. So I had the haematologist and gynaecologist both in support of diagnostic surgery for my abdominal pain. But it was still 'blocked'. I was not getting the surgery done. I have numerous letters but the end result was no surgery at this time.

165. I was referred by my GP (Dr Klazinger I believe). I had a 30 week wait. Finally saw Mr Bhalerao (consultant colorectal and general surgeon at Ysbyty Gwynedd Bangor. He said I possibly have a hernia. He said Dr Klazinga was planning a laparoscopy and CT scan of my abdomen. So he was going to wait for the results. I never saw him again, no follow up the 24th January 2015 last time I saw the surgeon Bhalerao.

166. In 2015, I attended a meeting with the surgical theatre manager who also convinced me that they had no issue with the surgery going ahead. But it was still 'blocked', I don't know why or who by, I will probably never know.

167. In the meantime, as I was in so much pain, I agreed to go on a hormone injection to treat endometriosis. A 'possible' cause of my abdominal pain needed Laparoscopy surgery to confirm/ rule out). I would have tried anything. For almost two years I was on these injections. They helped somewhat with the pain, but didn't get rid of it completely. Clearly I was better with them than without.

168. One day, the GP said that these injections are only for six months and not for long term use; she stopped them. The pain was soon back to being unbearable.

169. In 2016, I received help from the local Assembly Member of the Welsh Parliament, Siân Gwenllïan. On 19 December 2016, she informed me in the letter that she wrote to Gary Doherty, Chief Executive of the health board, outlining the mishandling of my health care and concerns of being on the at-risk register of vCJD (Exhibit **WITN4099011**).

170. In the above letter, local AM, Siân Gwenllïan also wrote that "*I have also referred you, as discussed, to the Community Health Council to help you with pursuing your formal complaint with the Health Board. They should be in touch shortly. I enclose contact details for the Community Health Council for your records.*" This is what led me to complain to the Community Health Council.

171. I pushed for answers, I had many questions, this spanned over the next 10 years.

172. To date I still don't know if I should be on the list or not. Judging by the standard of care from the health board, I can clearly state that they have treated me as if I have vCJD. But, Dr Hamilton maintains the risk is low.

173. I would like to state at this point from 2016, to this present day, November 2022, I have not received any correspondence from the Chief Executive of the Health Board.

174. In 2017, I was walking through the high street and I began struggling to walk. The pain on my right side was awful. In the end I went to A & E. I was given pain killers, and an agreement was made that I needed surgery to diagnose the pain.

175. I learned that the consultant haematologist and the gynaecologist who I was talking to throughout this process, were both no longer working in the hospital. So the two who I had regular contact with, and were in support of me having the operation, were gone. This left me under a new haematologist I cannot recall the name and gynaecologist, Dr Reik. It left me feeling as if I was going crazy, thinking *"Here I am back to square one dealing with consultants who don't know anything about my problems over the last five years"*.

176. The last time I saw my gynaecologist, Dr Klazinga was before the last meeting I had about the operation plans and vCJD concerns which was on 18 August 2015. That morning just before the meeting, we spoke. He told me he had been through my file and in fact, according to the government's guidelines, *"I don't believe you should be on this list"*.

177. The gynaecologist Dr Klazinga stated that *"According to your notes you have not been given the volume of plasma that deems you to be at risk of vCJD and actually I believe that they have mixed you and your mother up"*. I agreed with him that it was a logical explanation.

178. On 3 July 2017 at Ysbyty Gwynedd, I had a Diagnostic Laparoscopy, I finally had my exploratory surgery to diagnose my abdominal pain. I think this was a result of my visit to A & E and AM Siân Gwenllïan's involvement.

179. The diagnosis was abdominal adhesions on the right ovary stuck to the abdominal wall; bowel stuck to the uterus and several polyps and cysts. They were removed, sent for testing and apparently they were indescribable not cancer Carcinoma have my notes this is what it says and pictures on the adhesion. .DR Rieck written notes:
Surgeons / Dr ILYAS / Dr JAYANTH / Dr Rieck
'Diagnistic Laparoscopy and Hysteroscopy and Polypectomy and D&C'
Hysteroscopy 'Polyps removed'
Laparoscopy 'Adhesions post to umbilical & anterior abdominal wall' 'Ovary adherent to pelvic side walls' 'Adhesions in POD '
There are also photographs taken during the Laparoscopy

180. The ovary, it was successfully detached from my abdominal wall. Fortunately, no ovarian cancer was detected unlike in my late Grandmother. Had my test on the polyps and cysts been positive for cancer, I wouldn't have been writing this I would be dead for sure, I wouldn't be writing this.

181. Finally, I am pain free for several months. But gradually the pain has returned. More recently, I have had numerous lumps in the lower abdomen and a hernia. According to my scan report, there is something coming through the hernia. Therefore, I recently saw a general surgeon.

182. Surgery was not an option and he wasn't even open to the idea of removing one lump to diagnose me. He couldn't wait to get me out the door quick enough; infection risk was the only concern he had. There was no empathy for the pain I was in at all. I recognise his attitude and behaviour. I've been there before, from when I was treated in 2012. The problem is vCJD on my medical file.

183. In 2018, I had a Gynaecology appointment saw Dr U Majeed, who referred me back to general surgery, I saw Mr B Chaudhary 7th March 2019 with my abdominal pain swelling and adhesions. I attended an outpatient appointment in Ysbyty Gwynedd, Bangor. He said he thought I had problems with my large bowel after the examination.

184. On 23 March 2019, I had a CT scan. Dr Majeed wrote to tell me on the 26th March that the CT scan was entirely normal, no follow up needed.

185. I went back to my GP at Bron Derw Medical Centre, Bangor and explained that I was still in a lot of abdominal pain and discomfort. She sent me for an abdominal ultrasound which was done on 1 August 2019. The ultrasound results say there is *"diversification of the recti abdominis muscle. Small fat containing? Incisional hernia present"*.

186. I was scanned by Mr G. Rees and images were discussed by Mr G Rees and Consultant Radiologist, Dr C Barwick. This scan totally contradicts the recent CT scan report on the 21st March 2019 and the letter dated 26 March 2019 I received a letter from Dr B N Chaudhary, General Surgeon which states "You will be reassured to know that your CT scan has been reported entirely normal. You do not need any further input from the general surgeons".

187. However I have Copy of the CT scan report 21 March 2019 and it actually says I have a …'Hepatic CYST' so how is my CT scan "entirely normal"?

188. Mr G. Rees sonographer looked at CT scan images with me during my ultrasound appointment on 1 August 2019 he could see on CT scan images what the ultrasound picked up on. The diverticula and hernia were not reported, and were not included in my CT scan report 21st March 2019. I have copy of scan images.

189. I must add that I am worried about this cyst and don't know the cause, also it wasn't reported to my GP either - I had to tell them. I worry is it growing? how big is it now? Is it contributing to my abdominal pain, is it an infection? What if it busts? I worry I've been given no follow up or explanation

190. So I went back to the GP, Dr Stuart referred me to General Surgery on the 9TH August 2019 in 2019 questioning this, so he referred me back to Dr B N Chaudhary. I saw a member from his team. He said no to surgery but just went on about infection risks. My medical notes show that I saw Mr L Evans Specialist Trainee on the 14 Nov 2019.

191. More recently Dr Stuart referred me back again to the general surgeon 30 Sept 2021 with 'Chronic abdominal Pain' to date I've not received an appointment

192. In frustration, I requested copies of my medical notes and all scan reports. The CT scan does actually support the results of the ultrasound of my abdominal wall. Also I learned from the CT report that I actually have a cyst in my liver. To date, I have no idea what this cyst is and no follow up.

193. No one should have to fight for proper NHS care. I should not be treated any different to anyone else who doesn't have vCJD on their medical file. But sadly this is how things are for me, this is how I get treated. I will probably have to fight again with numerous telephone calls and meetings to find out what these lumps are. I feel too exhausted to do this all over again, especially since the death of my father in 2019.

Dental

194. More recently in 2020, I was diagnosed with a calcified lymph node under the right side of my jaw which is clearly visible on an x-ray. A maxillofacial surgeon, Dr Kamisetty requested an urgent ultrasound scan in January to be able to make a proper diagnosis, I'm still waiting for that scan and a proper diagnosis.

195. On 24 Jan 2020 I was referred by my dentist, I have notes 'Hard lump under right mandible' and 'referral has been triaged as 'accept oral surgery'…'Urgent 2 weeks' from the Dental Referral Management Centre.

196. Clinic date 8 Feb 2020, I saw Helena Dunning Oral and Maxillofacial Surgery Llandudno General Hospital. The follow up letter dated 15th Feb 2020 to my dentist from Helena Dunning 'There was a palpable lump'.
Clinic Date 15 June 2020 I see Mr A Kamisetty at Ysbyty Gwynedd
Letter Date 23rd June 2020 to my dentist from Mr A Kemisetty 'Diagnosis: Bilateral Cervical Lymphadenopathy
'I could palpate bilateral submandibular lymph nodes which were mobile.'
'Request ultrasound'
Clinic Date 13July 2020
Letter dated13 July 2020 to my dentist from MR A Kamisetty ' Diagnosis: Bilateral Cervical Lymphadenopathy" ultrasound did not show any obvious sinister features' ultrasound results not normal I have copy.

197. At this point Mr Kamisety told me it was not cancer yet, I thought here we go again and I asked for him to do a biopsy to be sure. He put request in, it was denied. I verbally complain, I'm not happy I don't know what the lump is no 'proper diagnoses' Again I don't know what's going on? He offered me a second opinion and I accepted.

198. 15th Oct 2020, I saw Mr C J Lloyd Consultant Oral Maxillofacial Surgery at Ysbyty Gwynedd, he told me he would review my medical notes see if he can come up with a diagnosis.
Letter dated19th Oct 2020 to Dr Stuart (at my doctors surgery) from Mr CJ Lloyd diagnosis this time is different, 'I could feel no Cervical Lymphadenopathy' (after pressure from me because I made it clear I wanted a proper diagnosis), they arrange blood tests, the notes say 'an MRI of the head and neck region although I think this will be normal' 'I think its unlikely that we will need to take matters further from the point of view of Maxillofacial Surgery'.

199. This is where things get strange. He can't feel the lump? My dentist, Dr Hellena, and Dr Kamisetty felt it and I still have it. It has not gone away. Mr Lloyd has Already summed up my MRI will be normal and don't need to be seen by them again before I have even had the MRI scan 'This is not right?' again I'm being fobbed off, suffering again. They've already decided to do nothing.

200. Not only have I not had a proper diagnosis. I have No lump apparently According to Lloyd. But why? (possible vCJD on notes) It's like a pattern of if we don't see it, it's not there with we don't have to deal with it. I am thinking is this the vCJD risk status causing this attitude or is it common practice within the NHS to cut costs? But given previous experience it's more likely to be the vCJD status. If Dr Lloyd had reassured me look it's defiantly not cancer ... but he has gone right the other way by saying he couldn't feel a lump.

201. I never saw Dr Lloyd again. I had several calls with Lynn his receptionist, I was told my MRI not normal with no explanation why. He says the neck is structurally normal. Whatever that means. There was no follow up. Letter Dated 7th December 2020 from Lloyd to dentist and Dr Stuart at my doctor surgery. 'no significant abnormality affecting your neck or face that I can determine' 'I hope this provides further reassurance for you.'
I would like to say I am not reassured not in the least.

202. Also the department told me in an email that they he even lost my x-ray that my dentist took and was included in my original referral from her (which lead to me being referred in the first place) I had to chase that up and ask my dentist to send another copy via email to Lynne Jones OMF Surgeons Receptionist.

203. Yet another reason to lose my mind and worry. Same pattern all over again. I give up, still to date have the hard lump in my neck, I have no idea what it is.

204. I was seen in Llandudno General Hospital by Helena, a member of Dr Kamisetty's team. She requested an urgent ultrasound scan on my neck, The letter 15th June 2020. The ultrasound was to be done at Ysbyty Gwynedd, Bangor. On 27 March 2020, I contacted the receptionist of Dr Kamisetty by telephone, concerned that I have not had my scan done. She put my call through to the scan department in Ysbyty Gwynedd hospital.

205. Given the fact that Covid-19 is affecting most of the outpatient appointments, I've been reassured that urgent appointments will go ahead, apparently except mine. I phoned the scan department I asked if scans were happening due to the covid situation, he told me 'we are only doing urgent scans' I told him mines urgent then he asked for my name and took a look, he told me its 'on hold due to Covid19, I doubled checked with him and asked if my scan was requested as urgent and he said ''yes' then he told me he would look at it and call me back... he didn't call me back.

206. Even though it says "*Urgent*" on my notes, it also says *"on hold due to Covid-19"*. They are contradicting themselves. I've seen this pattern of behaviour before, and I believe, that I'm on hold due to my vCJD status, and not Covid-19 issues.

207. On 10 June 2020, I called Dr Kamisetty's receptionist again letting her know I have not had a scan and I have another lump in my neck. She told me to take photos and email them to her. That afternoon I worried about my other lump and felt like something was getting worse and I needed treatment. I did an e-consultation with Dr Sain, at the Bron Derw Medical Centre (GP). I asked for antibiotics in case I had an infection and it was spreading. She prescribed me Clarithromycin tablets (antibiotics).

208. I later received a phone call to attend an outpatient appointment in Ysbyty Gwynedd, Bangor on 15 June 2020. I saw Dr Kamisetty and he said he doesn't think it's anything sinister but I needed to get an ultrasound scan as soon as possible. He phoned the scan department to try and arrange the scan. They said they are busy so they will phone me when they can get me in.

209. This is my experience with the Betsi Cadwaladr Health Board. The whole experience has had an effect on my immediate family as they have enough worry with my twin brothers. **GRO-C**

210.

GRO-C

211.

212. GRO-C

GRO-C The hospital mistakes have had a detrimental effected on my life and my family and now being told I'm at risk of developing the brain wasting disease vCJD due to yet again the hospital mistakes just awful its awful.

213. Hospitals are supposed to make people better not damage them, save lives not ruin them. This effect of possible having vCJD is horrendous. GRO-C GRO-C and now I too could have and could die of a vCJD brain wasting disease. I worry every day I could become the one who needs full time care due to this brain wasting disease, vCJD.

214. I fear I could become dependent on my son or my brother, Andrew. It's hanging over my head and my immediate families. I am being treated by the health board as if I am infected. I'm not getting the healthcare I need. They are expecting me to believe the risk of vCJD is low and yet they are treating me like a biohazard. I am tired and I want non-contradictory answers from the health board. I have had no support throughout this nightmare.

Psychological Support

215. On 26 January 2015 at an clinic appointment with Dr Hamilton Haematologist. I raised my concerns about cancelled operations due to vCJD being written on my notes. During this appointment she could clearly see I was in distress, she asked me 'would you like support from our psychologist?' I told her yes.

216. 30th Jan 2015 in a letter from Dr Hamilton it states 'I have also offered her support from Sally Burn our Psychologist who works with our service . she has agreed to this referral today.' I can state to date I have NOT received any invite to the support from Sally Burns I've never meet her.

217. I have been provided with a British Red Cross card from the Inquiry investigator. I understand that the British Red Cross provides services and works in conjunction with the Inquiry. I will consider making contact with them in the future.

218. The Inquiry has brought the following to my attention: the vCJD Support Network, a charity which provides emotional and practical support for all strains of CJD (www.cjdsupport.net).

Section 7. Financial Assistance

219. I did not apply for any financial assistance from any Trusts and Schemes. This is because I did not know anything about the schemes until the Inquiry investigator explained the history and the current status of Welsh Infected Blood Support Scheme ("WIBSS") and the vCJD Compensation Scheme. I contacted WIBSS on the 13th January 2021 I got the following email reply 'As vCJD is not covered under our scheme. I am afraid we cannot assist you'

Section 8. Other Issues

220. I don't believe that the Haematologist Dr Hamilton was being honest with me. Maybe she wanted to hide the fact I had been given plasma that I didn't need, or knows they had GRO-C up, or she knows I have vCJD somehow. I let the department take blood 2009 they told me it was to test my clotting levels but it's just a feeling something was not right here. I am thinking now what did they test?

221. To explain, she is the 'Haematologist' she should know the rules regarding surgery when it comes to vCJD thought plasma better than any other surgeon, it is her area of expertise. Dr Klazinger pointed out I hadn't been given the volume of plasma in the first place. GRO-C

GRO-C

222. Dr Hamilton had an opportunity to do what Dr Klazinger did and go through the rules regarding surgeries during a meeting or an outpatient appointment but she didn't. She referred me to the Piron Unit stating that I have mild Factor X1 Deficiency, even when genetic blood tests prove I don't. She says I have not been given an implicated batch.

223. I have been discharged by Dr M O Murtaza, Physician in Diabetes and Endocrinology with no explanation.
Letter dated 11th March 2019 to Dr Williams 'I will arrange further follow up for her in 3 months' time.' There was no follow up.
Letter dated 16th October 2019 to Dr Stuart 'discharging me back to the care of the GP'.

Exhibit Number	**Paras**	**From: 2020-03-10 Emails from Andrew Lock (brother) with documents.** **Document Title**	**Comments**
WITN4099002	**13, 18, 25**	**2010-12-03 Independent Complaints - Clinical Advisors Report re Julia Lock**	**Whole document**
WITN4099003	**38**	**2003 - 2015 Letters re no factor XI deficiency, cancellation of surgical procedures**	**Page 1 of 9**
WITN4099004	**40**	**2003 - 2015 Letters re no factor XI deficiency, cancellation of surgical procedures**	**Page 4 of 9** **[Same original document as above]**
WITN4099005	**42**	**2009-02 Generic Information for people at increased risk of CJD from Health Protection Scotland**	**All 6 pages**
WITN4099006	**45**	**2009-02-17 Letter from Dr Hamilton (North West Wales NHS Trust)**	**Pages 2-4 of 4**

WITN4099007	**48**	**2009-07 Notification Letter to JL**	**End of page 3 of 4**
WITN4099008	**49**	**2009-07 Notification Letter to JL**	**Page 3 of 4** **[Same original document as above]**
WITN4099009	**85**	**2013-09-25 Letter from Simon Mead (UCLH, Prion Clinic) to Dr Hamilton**	**End of page 2 of 3**
WITN4099010	**108**	**2011-06-15 Letter from Mary Burrows (Chief Executive, Betsi Cadwaladr, UHB) re complaint**	**Both pages**
WITN4099011	**129**	**2016 - 2017 Letters from Sian Gwenllian (Member of National Assembly of Wales)**	**Page 2 of 2**

Statement of Truth

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

Signed **GRO-C**

Dated 9/11/2022