

ANONYMOUS

Witness Name: **GRO-B**

Statement No.: WITN1387016

Exhibits: **WITN1387017- 23**

Dated: 31 March **2024**

INFECTED BLOOD INQUIRY

FOURTH WRITTEN STATEMENT

OF **GRO-B**

I provide this statement at the request of the Inquiry.

I, **GRO-B**, will say as follows: -

1. This is the fourth written statement I have provided to the Inquiry; my first statement dealt with my co-infection with HIV and HCV through the use of Factor VIII concentrates; my second statement dealt with my involvement with the MacFarlane Trust and my third statement addressed my campaigning work, particularly with the Birchgrove Group.
2. As I set out in my first written statement, I have severe haemophilia A and have, throughout my life, been treated with clotting factor products; until the introduction of recombinant products, these were manufactured from human plasma. These treatments infected me with (amongst other things) HIV and Hepatitis C; the British manufactured products also led to me being exposed to the new variant Creutzfeldt Jakob Disease ("nvCJD").
3. My Fourth Written Statement will deal with the problems I have experienced in trying to obtain endoscopy treatments as a result of having been exposed to nvCJD.

Relevant Chronology

4. In order to manage pain caused by haemarthrosis, I have long been prescribed non-steroidal anti-inflammatory medication; over time, this medication has caused me to develop stomach ulcers and I have a history of these ulcers dating back to approximately 24 years ago.
5. I receive haemophilia care from Dr Charles Percy at the Queen Elizabeth Hospital Birmingham ("QEHB"); Dr Percy is a Consultant Haematologist and the Director of the QEHB's Haemophilia Unit. I typically also receive gastrointestinal care at the QEHB because the haemophilia unit is on hand there to provide haemophilia cover for any procedure that I might require.
6. On 23 June 2020, I had a telephone consultation with Dr Percy which related to a conversation I had previously had with Mr Griffiths, an upper gastrointestinal surgeon at QEHB. In the conversation with Mr Griffiths, he had suggested an endoscopy take place in the latter part of 2020 to confirm whether it might be possible for me to stop taking Sucralfate; a drug used to treat stomach ulcers which I had been taking since a burst gastric ulcer in 2017.
7. In the first half of 2022, I had noticed changes in my bowel habits and blood when I went to the toilet; I saw my GP who referred me for a faecal immunochemical test which returned positive. As a result, I had a colonoscopy on 26 July 2022 which was undertaken at the Warwick Hospital by Mr George Galanopoulos. The colonoscopy identified a 6mm polyp in my transverse colon **[WITN1387017]**. The polyp was believed to be benign though a polypectomy was proposed subject to further discussions between Dr Percy and Mr Papettas, the Consultant GI surgeon at the Warwick Hospital.
8. On 12 August 2022, I attended an appointment with Mr Papettas who advised that the polyp be removed and biopsied; his subsequent letter (copied to Dr Percy) **[WITN1387018]** sets out that he considered me too young to simply leave the polyp in place and monitor it, that he believe it should be removed, and that he acknowledged my exposure to CJD which would require planning for an appropriate endoscope.
9. Four days later, on 16 August 2022, I had a telephone consultation with Dr Percy as part of his regular bleeding disorders clinic. I asked if I could take non-steroidal anti-inflammatory drugs again for my persistent joint pain but Dr Percy was still concerned

ANONYMOUS

- about writing a prescription due to my history with stomach ulcers. Dr Percy said that he would request an Oesophago-Gastro-Duodenoscopy (“OGD”) be carried out at QEHB to first ensure that there had been no recurrence of my stomach ulcer – this would turn out to be the endoscopy procedure first recommended by Mr Griffiths in July 2020. Dr Percy also said that he was waiting to hear from Warwick Hospital following my colonoscopy.
10. On 24 September 2022, Dr Percy referred me to Mr Ward who is the Consultant Colorectal Surgeon at QEHB [WITN1387019] in order that the polypectomy recommended at my August consultation with Mr Papettas could be undertaken. I attended Mr Ward’s clinic to plan the procedure on 13 January 2023.
 11. The OGD Gastroscopy requested by Dr Percy in August 2022, was undertaken by Mr Gianmarco Contino on 11 April 2023 and he identified a pylorus polyp with a fibrin cap which was suggestive of recent bleeding. It was recommended that I undertook a course of high dose protein pump inhibitor medication which inhibits the stomach’s ability to produce acid; I was then to be seen a further 6 to 8 weeks later. Ultimately, Mr Ewen Griffiths, Consultant Upper Gastrointestinal Surgeon at QEHB advised Dr Percy against my further use of non-steroidal anti-inflammatory medication.
 12. On 27 June 2023, Dr Percy wrote Mr Griffiths querying whether I should have a further OGD Gastroscopy to reassess the polyp found on 11 April 2023 because biopsies of that polyp had shown areas of ulceration and inflammatory change which appeared hyperplastic (an early indication that the polyp might be cancerous).
 13. At this stage then, two polyps had been identified at separate locations in my body; first, a polyp in my transverse colon which was discovered on 26 July 2022, and which appeared benign; second a pylorus polyp with a fibrin cap, discovered in my stomach on 11 April 2023 which appeared may be potentially cancerous.
 14. I received an appointment with QEHB’s endoscopy department for 5 August 2023; it is not entirely clear to me which polyp this appointment was intended to address but the appointment came with a leaflet titled “Having a Flexible Sigmoidoscopy” which explained that this was a technique to look at the lining of the colon and take biopsies which led me to believe that this would be a procedure directed towards the polyp in my colon.

ANONYMOUS

15. In any event, I attended the appointment on 5 August 2023, which was a Saturday and, as a result, no haemophilia cover was available. The procedure was cancelled, and I was sent home; no explanation was offered as to why the appointment had been made on a Saturday when it was known that I would require haemophilia cover and I was told that the endoscopy department were unable to access my hospital notes.
16. A further colonoscopy was scheduled for 20 September 2023 where I understood that the polypectomy of the polyp in my transverse colon would be performed. I attended the appointment and was (as is routine) asked about my medical history. As always, during the course of this discussion, I again confirmed that I had been exposed to nvCJD through human-derived, pooled-plasma products. The nurse seemed surprised at this and asked if I had understood the question properly and then, how did I know that I had been exposed – I told her that I had a letter from QEHB confirming it. The nurse went away to speak with a senior colleague. It is important to note that there was nothing in my QEHB notes about having been previously exposed to CJD.
17. After the nurse left, I changed into a surgical gown and sometime later, I was taken to the operating theatre and asked if I knew what procedure I was about to have; I said that I was there to have a polypectomy and biopsy and I remember a doctor giving a non-committal response. A cannular was then inserted into my arm to deliver the sedative when there was a knock at the door and Senior Sister [GRO-D] entered saying that the procedure could not go ahead as there was an issue. I was extremely angry and asked if this was because I had prior exposure to CJD? The Sister didn't deny that it was and I told her that the QEHB's policies were supposed to have changed so that this wouldn't be an issue anymore; I insisted on the procedure going ahead.
18. A procedure did go ahead, Drs [GRO-D] and [GRO-D] carried out a colonoscopy. I asked at the end of the procedure about the removal of the polyp and was told that the procedure was only for screening and that in any event, no polyp had been found [WITN1387020].
19. Immediately after the appointment, I went to the haemophilia unit knowing that one of the haematologists would be there as the unit had to provide cover for my colonoscopy; I relayed the experience I had just had and was left with the impression that it was far from unique amongst the haemophilia patients treated at QEHB.
20. During November 2023, I spoke with Dr Percy again during his bleeding disorders clinic and he picked up matters about the colonoscopy with Mr Ward; Mr Ward advised that

ANONYMOUS

a CT Colonogram should be undertaken to be completely sure that the polyp had not been missed at the Colonoscopy on 20 September.

21. On 10 January 2024, Dr Percy told me that the CT scan had revealed a 9mm pedunculated polyp in the large bowel, that he had spoken with Mr Ward and that Mr Ward had recommended a further endoscopy. Dr Percy confirmed that both he and Mr Ward had been in touch with the QEHB's endoscopy department to ensure appropriate measures were in place concerning my exposure to CJD. I subsequently received an appointment for the endoscopy to take place on 14 March 2024.
22. On 23 February 2024, I received a telephone call from QEHB to tell me that the procedure had been cancelled because no appropriate instruments would be available on 14 March; no alternative date was offered and the person who called me could offer no explanation, she said that she had asked for the reason but not been given one.
23. The same person called me back on 1 March 2024 and asked if I would consider having the procedure undertaken at another hospital such as Birmingham Hartlands. I said that this would be impossible because Birmingham Hartlands didn't have a haemophilia unit to provide cover in case I bled; I asked if this was related to my CJD exposure and how it was possible to have the procedure done elsewhere unless QEHB had policies that were different to other hospitals.
24. Following this call, I contacted the Haemophilia Society and Kate Burt, the CEO, took the issue up with Matt Metcalfe, Hospital Executive Director QEHB [WITN1387021]. He responded on 7 March 2024 [WITN1387022] with an email to me and Kate. He said he was sorry to hear of my experiences and was following up by formalising the complaint through the hospital complaints process. I responded to him on 11 March 2024 explaining the concerns I had in respect of my physical and mental health due to the high on 2-year delay in having the polyp removed and biopsied as well as the implications of the delay given the nature of the infections I had been given by the QEHB treatments, and resultant health issues. I asked him if he could give a timescale for a response to my complaint as the longer it went on, the more concerned I was for my health and for other haemophiliacs who are being, or will be, discriminated against if and when they require an endoscopy at QEHB. Matt Metcalfe emailed a response that same day and copied it to Jo Basketfield, QEHB Director of Nursing [WITN1387023]. He stated that Jo would ensure there would be a plan for my procedure which is robust and did not let me down again. Jo Basketfield responded saying she would definitely pick this up.

Issues

25. As matters stand, I have a polyp in my stomach which was determined to be potentially cancerous and which remains untreated almost exactly a year later as well as a polyp in my colon which remains in-situ and unbiopsied some two years after discovery during the course of which time, it has grown by 50%.
26. I am obviously concerned about the implications of these delays for my own health but I am also concerned about how QEHB's policies are affecting all of those with bleeding disorders at QEHB. I hope that I will shortly receive an appointment which will ensure that both of my polyps receive the attention they deserve but I should not have to fight a rolling battle with QEHB just to get the care which has been recommended by those treating me. It has taken a letter from the CEO of the Haemophilia Society and the threat of legal action to persuade the QEHB to take the matter seriously.
27. There are policies in place nationally which are meant to ensure that those who have been exposed to CJD can still access the care they need; there is no excuse for how the QEHB are either ignorantly or obstinately disregarding these policies and putting the health of haemophiliacs, including my own, at risk.
28. Moreover, the QEHB's approach is all the more inexplicable when one considers that those exposed to CJD were given a choice as to whether they wanted to know that they had been exposed; if I had chosen not to know then, taking account of the fact that QEHB's records are silent on my exposure, the various endoscopy procedures planned for me would have gone ahead without any concern, presumably using regular, pool endoscopes.
29. In my opinion, all patients should be treated as potential carriers of infections (including CJD) and accordingly, all instruments should be cleaned to the highest possible standard in order to preserve the health of all patients.

Addendum

As this statement was about to be submitted an appointment was made for the removal and biopsy of the polyp in my transverse colon; the appointment has been made for 28 March 2024 and I will update the Inquiry if this appointment does not go ahead.

Statement of Truth

I believe that the content of this statement is true.

Signed:.....

GRO-B

GRO-B

Dated this day of March 2024