

Witness Name: Simon Hamilton

Statement No: WITN2339012

Exhibits: WITN2339013-

WITN2339043

Dated: 25th August 2020

INFECTED BLOOD INQUIRY

THIRD WRITTEN STATEMENT OF SIMON HAMILTON

I provide this statement in response to a request under Rule 9 of the Inquiry rules 2006 dated 13th January 2020. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Simon Hamilton, will say as follows: -

Section 1: Introduction

1. My name is Simon Hamilton. My date of birth and address are known to the inquiry.
2. I am a haemophiliac and have contracted Hepatitis C ('hep C') through contaminated blood products and subsequently developed cirrhosis of the liver. I am the Chairman of Haemophilia Northern Ireland ('HNI'). I make this statement in relation to my campaigning activities. Previously, I provided a witness statement to the Inquiry regarding my infected status as a haemophiliac living with hepatitis C and cirrhosis on the 14th March 2019 (WITN2339001). I then provided a second statement to the Inquiry after viewing my medical records (WITN2339002).

Section 2: Organisations Involved in Campaigning Activities

1. HNI formed in September/ October of 2017. A collective group of individuals chose to form HNI in order to advocate, support and provide advice for sufferers of haemophilia, Von Willebrands and other bleeding disorders with a specific focus on sufferers in Northern Ireland.
2. Belfast City Hospital has a large haemophilia clinic and it is where most Northern Irish haemophiliacs receive their treatment. One day, in mid-2017, I was speaking with retired nurse, Collette McAfee at the hospital's haemophilia clinic. She told me how some haemophiliacs who attended the clinic did not feel as though their voices were being heard. When I say voices being heard, I mean they felt as though their cause was not represented in Northern Ireland, an effective support system was not in place. Specific reference was also made to the fact that haemophiliacs did not feel represented by the Haemophilia Society. This conversation and the lack of support for haemophiliacs in Northern Ireland were the main catalysts for forming HNI. When HNI was initially set up, retired nurse Collette McAfee became a treasurer of the organisation.
3. Another motivation for creating HNI was to provide support and educate mothers of young boys with haemophilia. I found that mothers in Northern Ireland did not have a community or support system they could utilise or ask questions to about how to manage treatment for their young boys. Here, in Northern Ireland there wasn't a place where these mothers could meet. Therefore, one of HNI's objectives since its creation has been to provide this support and help educate these mothers.
4. Since HNI's formation in 2017, we have hosted a number of social and charitable events. I will go into detail about these events later on in my statement.
5. Above, I touched on the Haemophilia Society and the general feeling they were not providing effective representation in Northern Ireland. In the late 1980s through to the early 1990s, I was a member of the Haemophilia Society and my

brother, Nigel was a trustee of the Society. I believe Nigel was a trustee around the same period I was a member but was more actively involved with the society being a trustee. In the past, they had a presence in Northern Ireland and owned two caravans here. The caravans were used by members if they wanted a weekend break. However, by the end of the 1990s, the Haemophilia Society's advocacy for Northern Irish haemophiliacs appeared to stop. All their great events also stopped.

6. An organisation like HNI was desperately needed even before it's establishment in 2017. One of HNI's main objectives was to raise awareness of haemophilia in Northern Ireland in and to provide support to haemophiliacs.
7. One of the biggest motivations for HNI's creation was the outcome of the Penrose Inquiry which published its final report in 2015. My belief that the Penrose Inquiry was a whitewash is one that is shared by many victims and their families who have been affected by contaminated blood. I felt the Penrose Inquiry did not provide justice or recompense for victims of contaminated blood in Scotland. There was a void in Northern Ireland that needed to be filled, support for victims of contaminated blood was necessary and this had been neglected for quite some time.
8. I am good friends with Bill Wright of Haemophilia Scotland. We share very similar beliefs and I believed HNI could learn a lot from his leadership of Haemophilia Scotland. Haemophilia Scotland is a successful charity and has carried out some excellent work. Bill has set a fantastic example and a number of us wanted to follow in his footsteps by forming a charity in Northern Ireland that shared similar objectives. In 2017, myself, Bill and six other founding members of HNI had a meeting in Belfast. We discussed the best approach for setting up an effective and workable group in Northern Ireland that represented not only haemophiliacs but those who suffered from other bleeding disorders.
9. Following the meeting in Belfast we looked at ways we would be able to get in contact with other haemophiliacs in Northern Ireland. I contacted the Haemophilia Clinic at Belfast City Hospital and asked whether they would be

able to put us in contact with haemophiliacs who attend the clinic. However, we soon realised that GDPR would be an issue and this prevented the clinic from sharing this information with us.

10. HNI set up a Facebook page. We found this to be an effective and very useful way of communicating with the haemophilia community in Northern Ireland. We also put up posters in and around Belfast City Hospital. Overall, we received a pretty good reception. Although it soon became apparent that using the Facebook platform would be the most effective way of communicating with our target audience.

11. All members of HNI are volunteers, none of our members are on a salary. HNI is a small organisation, our average turn-over varies between £6,000-£10,000 a year.

12. Following the creation of our Facebook page, at the beginning of 2018, HNI began to focus its energy on the education of young haemophiliacs. We collaborated with a Dutch publisher and authored a book on how haemophiliac children can self-treat and handle bleeds. The book was illustrated as such that it would capture the attention of a younger audience. The purpose of the book was to instil confidence in young haemophiliacs and to inform them on how to manage bleeds and keep healthy.

13. In early 2018 HNI became involved with the Public Inquiry which I will detail later in this statement.

14. We continued to support families and remain active in the Haemophilia community in Northern Ireland. During autumn 2018, we held a family event at a cafe where all sorts of board games are played. This was very successful, we had a number of games for the children and we mingled with parents and were able to speak with the parents of those children, offer support and guidance. This event was successful, and we went on to host a Christmas event later in the year and another one in 2019. Around thirty families attended the event and afterwards we found this was an effective way of getting the community

together. I refer you to **Exhibit WITN2339013** these are photographs from the event.

15. In 2019 we held our annual family day at the Crumlin Road Prison Visitor Centre. During the event we had doctors and nurses from Belfast City Hospital Haemophilia Centre speak and offer advice on how best to manage bleeds. At the event, we also hosted a practical fun workshop for young people on prophylaxis and preventable health care. One of our committee members - a paediatrician - also hosted a workshop for young mothers and children. Representatives from Haemophilia Scotland also spoke at the event and hosted a workshop for women sufferers and carers and there was a workshop for older men who suffer with haemophilia.
16. In Christmas of 2018, HNI held a Christmas Santa trail. Over 30-50 people attended this event. I refer you to **Exhibit WITN2339014** which are photographs of the event. The event was hugely popular with families and really helped us garner more support. We held a similar event at the Titanic centre the following Christmas (2019) and will be holding another event like this in 2020 Coronavirus pandemic conditions permitting.
17. This year we had planned to host a mothers' event. However, this has been cancelled due to the Coronavirus pandemic. HNI had another family event scheduled for May this year, this was going to be held at Ulster American Folk Park in Omagh. Although we have since postponed this due to the current lockdown.
18. I am the Chairman of HNI, and I drafted our constitution. The HNI constitution was updated in May 2020 and a copy of the constitution can be found at **Exhibit WITN2339015**.
19. My brother Nigel was going through treatment for liver cancer and was back and forth to the hospital when we elected HNI committee members in Autumn 2017. I was elected chairman of HNI. My main role as chairman is to support

committee members and help manage sub-committees concerning; events, young people, mothers and the public inquiry.

20. Nigel's role has been centred around advocacy for an inquiry into contaminated blood. Out of the members of HNI myself and Nigel have been most involved in advocating for the Inquiry.
21. Many members of HNI have not been affected by the contaminated blood scandal and we did not want the organisation to be solely focussed on the scandal. However, Nigel and I were both massively affected by the scandal and wished to meet others who shared similar experiences. Nigel and I are HNI's Public Inquiry representatives.
22. HNI's committee consists of six active committee members. We mainly host meetings in Belfast. In Belfast, the meetings have taken place at Belfast City Hospital and at my workplace. HNI has also hosted meetings at the medical school at Belfast City Hospital.
23. Following HNI's establishment in autumn 2017 the committee became serious about getting the organisation registered as a charity with Northern Ireland's Charity Commission. HNI reached the 'pending level' with the Charity Commission which meant that we have come close to achieving charity status with the commission. However, the Commission has encountered some staffing and administrative difficulties and the process of moving us to 'fast track' has been considerably slow. HNI wrote to Sir Brian in 2018 regarding the position with the Commission. Jennifer Cole of the Inquiry agreed to write to the Commission to assist us to hasten the Commission stating the value of our role at the Inquiry and how recognition of our status would assist our advocacy role in the Inquiry. This was on the advice from the commission but achieving charitable status. We later received a letter from the Northern Ireland Charity Commission that informed us our application had been fast-tracked. However, we are still not a registered charity even though we were notified our application had been fast-tracked. We have been waiting for around 3 years for our charity to be registered by the Commission.

24. Due to management issues surrounding the Charity Commission it is likely that we will have to re-apply in order for HNI to become a registered charity.

25. The turning point for HNI came in March 2018, when my brother Nigel made contact with Michael Imperato of Watkins & Gunn solicitors in South Wales. Nigel had heard that the British Government were proposing to commission a national inquiry into the contaminated blood scandal. Following Nigel's discussion with Michael, Watkins and Gunn became our legal advisors when the Inquiry began. After that initial contact with Michael, it felt as though we finally had a plan in place in terms of what we wanted to achieve with the Inquiry.

26. Nigel and I drafted HNI's Terms of Reference for the Inquiry. A copy of this can be found at **Exhibit WITN2339016**. As you will see at the beginning of the exhibit, one of the main aims and objectives of HNI was "to provide both accessible and informative communications for those who require timely and regular feedback on the progress of the Infected Blood Inquiry until its report has been concluded". As an organisation that represents a community here in Northern Ireland, it was imperative that we had a written document we could refer to, so we were able to keep a track of our objectives. **Exhibit WITN2339016** also refers to how HNI would be interacting with their legal representatives Watkins and Gunn.

27. My legal representatives have been wonderfully helpful. When we began working with them, they threw out support for anyone who was affected by contaminated blood not just HNI members but all victims in Northern Ireland.

Section 3: Involvement in Committee and/or working groups

1. Please note this section also covers section 5 titled "Individual Campaigning Activities".
2. I began lobbying and campaigning in 2015. I had a realisation that something needed to change for contaminated blood victims. I sent a letter in early 2015 to Member of Parliament for Upper Bann, David Simpson. **Exhibited before**

me at WITN2339017 is a letter from Mr Simpson dated 15th February 2015. In the letter, Mr Simpson reassures me he will be discussing the issues I have raised with him in Parliament. The main issue I raised with him was in relation to an increase in payments for blood victims and their families. The letter demonstrates that I was raising these issues with members of parliament as far back as 2015.

3. In 2016, in the aftermath of the Penrose Inquiry, I wrote to all Northern Irish MP's. I desperately wanted to raise awareness and shine a light on the struggle contaminated blood victims and their families were facing in Northern Ireland. In 2016, it came to my attention that England was proposing to hold a consultation on infected blood payments. I wanted to know whether a similar consultation would be carried out in Northern Ireland. I wrote to leader of the Democratic Unionist Party in Westminster, Nigel Dodds, in early 2016 about the consultation. I received a letter of reply from Mr Dodds on 18th February 2016. The letter of reply is **Exhibited before me at WITN2339018**. Mr Dodds informs me in the letter that *"any changes to health schemes in England does not mean there will be automatic changes to any such schemes in Northern Ireland"*. The response was disappointing but expected.
4. Not only did I write to Northern Irish MP's but also to Members of the Legislative Assembly ('MLA') here in Northern Ireland. I felt as though lobbying for a national Inquiry and parity was the only way forward after Penrose. I wasn't going to stop pushing the issue and wrote to the Member of Parliament for South Down, Margaret Ritchie. I raised concerns with Margaret Ritchie MP about the ex-gratia schemes in place in Northern Ireland. I received a response from Margaret Ritchie MP on 17th February 2016. In her response Ms Ritchie states, she had made representations to the government with my concerns. This response is **Exhibited before me at WITN2339019**.
5. On 17th March 2016, the Department of Health replied to Margaret Ritchie's representations. The letter **Exhibited before me at WITN2339020**, states the Department of Health is carrying out a consultation about the discretionary payments made by ex-gratia schemes regarding travel and accommodation.

The letter does not make reference to any other type of discretionary payments and explicitly states *“the scheme bodies have been clear that any discretionary payments they have made to registrants of the scheme will not necessarily continue to be made in the future”*. On page 2 of the letter a similar tone is used by the Department of Health as they again state *“The Department’s funding for these payments and those through the other schemes that have been established are ex-gratia which means they are voluntarily made by the government”*. Again, the Department of Health are making it clear that these payments are on a voluntary basis and are a result of the governments good will.

6. The letter did not provide me with any confidence that any change was on the horizon for Northern Irish victims and their families with this exemplified through the Department of Health’s assertions that they would be carrying out a consultation regarding travel and accommodation for victims and their families in England. There was no discussion of a consultation on a payment uplift for any victims and their families in the devolved nations at this point in time.
7. On 30th March 2016, I received a letter from Sylvia Hermon MP. In the letter **Exhibited at WITN2339021**, she states, that a consultation on financial assistance would provide a good opportunity for many victims to offer their views. In the letter she discusses the consultation I refer to above. Ms Hermon says the consultation is regarding financial assistance schemes in England and this again made me question why a consultation like this wasn’t taking place in Northern Ireland. The letter also states that Simon Hamilton MLA and Minister at the time for Social Services and Public Safety had been in contact about the consultation and its affect in Northern Ireland. However, it is disappointing that the letter invited individuals across the UK to participate in the consultation, but this seemed like a pointless exercise when their views were not going to be considered by the respective devolved nations.
8. In 2016, there was little progress or change for victims in Northern Ireland. As demonstrated above, I wrote many letters. However, as you will note in the

documents exhibited above many of the responses, I received were England centric and did not apply to Northern Irish victims.

9. I was however grateful to receive a call from a representative of the Secretary of State for Northern Ireland, Julian Smith MP, thanking me for all the work I had been doing for Northern Irish victims in regard to payments. Mr Smith advised me that there had been a political breakthrough which included a commitment to achieve parity in the 'New Decade New Approach' document that was published with the return to devolution. It was good to feel as though my letters and correspondence with political figures and departments was being recognised. Unfortunately, those commitments have still not been met.

10. In July 2017, it was finally announced that a UK-wide Inquiry was going to be held into the contaminated blood scandal. It was also announced the Inquiry would be chaired by Sir Brian Langstaff. I was very pleased the Inquiry had been announced and shortly after the announcement I began to think of how I would participate in the Inquiry and how victims in Northern Ireland would be represented.

11. As I have already stated at paragraph 6, section 3 of my witness statement, in March/April 2018, after Nigel made contact with Michael Imperato of Watkins and Gunn, we began to consult on responding to the Inquiry's Terms of Reference. I refer you to **Exhibit WITN2339022**- this is a copy of Haemophilia Northern Ireland's response to the Inquiry's consultation on its Terms of Reference. At section 4 of our response we set out that the Inquiry should cover the following;
 - a. *"Why patients were given infected blood and blood products when treated by the NHS;*

 - b. *The extent to which this continued after the NHS and/or Government was or should have been altered to the risks, and why it continued to happen;*

 - c. *Why it was that blood products had to be purchased abroad rather than sourced locally; and*

d. Whether there was a deliberate attempt to conceal details of what had happened, both at the time it occurred or later"

12. At section 5 of **Exhibit WITN2339022**, you will note that we ask the Inquiry to investigate the *"extent of any differences in Northern Ireland"* in terms of decision making. Contaminated blood was given to individuals in the 1970s and 1980s, a time when health was not a devolved matter in Northern Ireland. One of Haemophilia Northern Ireland's main objectives is for the Inquiry to make clear who was calling the shots in Northern Ireland at the time of the scandal and whether this was indeed a devolved matter. The Governance of Northern Ireland was complicated from the time of the troubles with Home Rule, Direct Rule, a mixture of both and finally devolution. It is important that the inquiry examines this in the context of who was making decisions which impacted on the victims of contaminated blood here. Who was responsible, who is accountable?

13. The Inquiry's Terms of Reference were unveiled on 2nd July 2018 in London. Around the same time HNI responded to the Inquiry's consultation on its terms of reference, we also felt as though we needed to provide some background on the position here in Northern Ireland and the reasons behind HNI's formation. **Exhibited before me at WITN2339023** is a copy of HNI position paper from 2018. The position paper provides a background as to how health and social care is managed by the various health boards in each Northern Irish county. More importantly, the position paper sets out the rationale for HNI's creation. You will note at page 11 of **Exhibit WITN2339023** that the stagnant political situation in Northern Ireland was a real catalyst for HNI's creation. HNI's representation of 300 Northern Irish victims and their families in the Inquiry was crucial as it meant we had a duty to ensure that despite the political upheaval in Northern Ireland victims would have their voices heard through providing witness evidence (both written and oral) to a UK led Inquiry.

14. Before the beginning of the Inquiry, Nigel and I met with our legal representatives in Belfast in August 2018. During the meeting, we mainly discussed a number of matters that would be relevant to Lloyd Williams QC's

speech and how Northern Irish victims' experiences would be referenced in this. We also discussed the health and political system in Northern Ireland and how they differed to the other devolved nations.

15. Through the help of my legal representatives HNI were able to build a working relationship with Belfast Health and social Care Trust. Once the Inquiry commenced in 2018, HNI met with the Chairs of Belfast Health and Social Care Trust on a number of occasions. During the meetings the trust agreed that they would fast track the records of not only haemophiliacs that were taking part in the Inquiry but also those who had been infected via blood transfusion. I would like to add that our legal representatives at Watkins and Gunn attended these meetings and organised these meetings. I have **Exhibited before me at WITN2339024** correspondence dated October 2018 between my brother Nigel Hamilton and the Belfast Trust Director of Surgery and Specialist Services, Caroline Leonard.

16. I was very impressed at the fact that victims represented by Watkins and Gunn in Northern Ireland had relatively few problems accessing their medical records. I believe that the meetings attended by myself, Nigel and our legal representatives played a huge part in this.

17. I have observed a number of individuals at the Inquiry's engagement meetings stating that they have encountered problems accessing their medical records. I believe the effective advocacy of our legal team has enabled a lot of individuals to access their medical records.

18. Throughout the Inquiry we maintained a good rapport with the Belfast Health and Social Care Trust. When we have requested updates from them regarding victims accessing their records we have been provided with these updates. A meeting took place between the trust, myself, Nigel and our legal representatives in January 2019. During the meeting it was discussed that patients and their families had better access to their medical records but that this could be improved. **Exhibited at WITN2339025** is email correspondence from Caroline Leonard of Belfast Trust to my brother Nigel dated 6th February

2019. The correspondence provides an insight into the type of discussions that have taken place between ourselves, the Trust and our legal representatives.

19. At the final few meetings with the Trust, the Director of Mental Health attended. I think as soon as the Inquiry had begun to highlight the enormity of the impact this was having on individuals' mental health the Trust took note accordingly. However, I would like to add that victims have lived through that trauma long before the Inquiry started in 2019 and mental health support was never a part of a Trust support strategy.

20. In my first witness statement to the Inquiry I discuss Dr **GRO-D** and the fact she had stated haemophiliacs that attended Belfast City Hospital were offered counselling. This was not true. A pamphlet was given to Northern Irish haemophiliacs which explained what HIV and hepatitis C were but they did not list or sign post any mental health services.

21. The Inquiry opened in September 2018 with its Preliminary Hearings taking place in London. However, back home in Northern Ireland the lack of financial remedy for victims and their families had stayed the same. This has become a major issue of contention for victims.

22. On 15th October 2018, following the month of preliminary hearings, Sir Brian Langstaff wrote to David Lidington, the Cabinet Minister by now responsible for the inquiry, calling for action on financial support sooner rather than later for victims. In his letter Sir Brian called for an urgent response so victims and their families needed to live rather than exist.

23. Mr Lidington responded in November 2018 stating this was a devolved matter, a response which instilled very little confidence in myself. The response dated 18th October 2018 is **Exhibited before me at WITN2339026**. Disappointed with this, a collective of the various Haemophilia charities and campaign groups across the UK came together and wrote to the Prime Minister. HNI was one of those campaign groups fighting for infected blood victims.

24. The various charities and groups across the UK who had written to the Prime Minister were offered a meeting in the New Year of 2019 with the Minister and officials at Portcullis House in 22nd January 2019.
25. Prior to the meeting at Portcullis House, the collective groups held a virtual preliminary meeting in December 2018 to discuss an agenda for the meeting and another meeting in early January 2019 at the Work and Pensions Office in London. During the second preliminary meeting we were optimistic we would make progress.
26. At the meeting at Portcullis House held on 22nd January 2019, representatives from Haemophilia Wales, Haemophilia Scotland, Haemophilia Society UK, Factor VIII campaign group, Birchgrove, Contaminated Blood and HNI came together with David Lidington MP acting as the government representative and Junior Health Minister Jackie Doyle-Price. During the meeting it was stated that £55 million was the roundabout figure which would resolve the parity issue across the devolved nation. During the meeting David Lidington MP asked simply "how much is this going to cost?".
27. HNI had a few meetings with the Permanent Secretary for Northern Ireland's Department of Finance, Sue Grey (who is also senior sponsoring officer for Inquiry). I had unique access to Ms Grey and attended several meetings which were mainly focussed on increased financial support for blood victims in Northern Ireland. I will discuss these meetings in greater detail later in my statement.
28. In April 2019, a payment uplift was suddenly announced for victims in England. The overall increase in payments went from £46 million to £75 million. However, in Northern Ireland there hadn't been an increase and there wasn't any sign that an increase was on the horizon. I felt that after the meetings that had taken place in January 2019 we had been given false hope by being left out of the arrangements we had advocated for.

29. The collective groups wrote to Theresa May on 8th May 2019 regarding the payment uplift for England. The letter requests that payment uplifts are made across all of the devolved nations. A copy of the letter is **Exhibited before me at WITN2339027**.
30. In May 2019, during the Belfast Hearings, I gave evidence to the Inquiry. I felt as though the hearings were a success and allowed people to engage. Victims were also able to support one another. I felt comfortable giving evidence and felt as though I was in a safe environment. People in Northern Ireland (and I can't speak for them all) tend to be quite private people. It was a very significant moment when victims and their families stood up and gave evidence in Belfast.
31. During that week myself and my brother attended the hearing days and this helped raise the profile of HNI and to emphasise that we wanted to assist all victims. We again had fantastic support from our legal team. There was a real collective sense of unity amongst the victims and their families.
32. Nigel and I also gave a number of interviews to local media. Again, this raised the profile of HNI and also, importantly, the plight of victims generally in Northern Ireland.
33. Around the same time Nigel, GRO-C lobbied his MP, Paul Girvan, who raised the parity issue with Jackie Doyle-Price during parliamentary questions. **Exhibited before me at WITN2339028** is a copy of the response Mr Girvan received to his question, dated 5th June 2019. In her response Jackie Doyle-Price states *"I have written to my counterparts in all the other devolved nations including the Permanent Secretary of Northern Ireland... A date for this meeting is currently being sought"*. It became increasingly clear around this time that the Northern Irish government needed to enact a similar change to their English counterparts, the disparity between the two nations had never been so obvious but the issue, again, was considered a devolved matter.

34. In the months between May and October 2019, I again wrote to several politicians

35. A meeting in Westminster between the devolved governments' Departments of Health representatives was scheduled for 10th July 2019. Sue Grey was also due to be present. Ms Grey and I have developed a good working relationship and I have found it very useful to be engaged with someone who communicates directly with the UK administration.

36. Theresa May's premiership concluded in July 2019. Meanwhile, Civil Servant Sue Grey introduced me to Nick Hurd. Nick Hurd was the former Minister of State for Northern Ireland between 2018-2019. **Exhibited before me at WITN2339029** is my letter to Nick Hurd dated 1st August 2019. When I drafted the letter, I wanted to open up the lines of communication with Westminster officials and it worked. Mr Hurd had been a responsible minister at the beginning of the Grenfell crisis and came from an empathetic position regarding victims. Through our meetings and contact with the health board, he developed a good understanding of the situation here in Northern Ireland and I was able to demonstrate to him how the health board had initially been a stumbling block to parity. Unfortunately, he withdrew from office over a difference of opinion on the EU before he could advocate meaningfully for our case.

37. By October 2019 it had been a year since the Inquiry had begun and a year since Sir Brian wrote to David Liddington, Chancellor for the Duchy of Lancaster, regarding the financial uplift that was needed for victims. I wrote to Sir Brian on 16th October 2019 by way of update and with particular focus on issues facing Northern Irish victims and their families. A copy of the letter can be found at **Exhibit WITN2339030**.

38. At the same time, representatives of the various campaigning groups (including HNI) wrote to our new Prime Minister Boris Johnson in October 2019. The letter again urged the leadership to provide a financial uplift to all UK Nations not just England. A copy of the letter dated 16th October 2019 is **Exhibited before me at WITN2339031**. We received a letter of reply from the Prime Minister on the

21st October. The reply stated, *"The Government will give the most urgent consideration to any recommendations made by the Inquiry"*. You will note in the response from the Prime Minister **Exhibited at WITN2339032**, that no firm assurances are provided regarding the parity issue. It is not unreasonable upon reflection to view this as a highline comment which continues - like other previous Prime Minister letter commitments to be of little worth. I wonder how significant recommendations could be honoured when the small issue of parity has been so deliberately obfuscated.

39. 2020 marked a new decade and I felt positive. In January 2020, the various charities and groups, who had worked together the previous year, again met virtually via remote streaming service. (Members of other campaign groups were later also invited to meet the new Cabinet Minister however I am unsure of the names of all of the organisations). This was a preliminary meeting between the groups before a meeting with Ministers later that month. The purpose of the meeting was to prepare our arguments and what we wanted to convey to the Ministers and members of the Civil Service.

40. On the 26th January 2020 the Health Minister Robin Swann announced payments for people who were diagnosed with Hepatitis C or HIV after receiving NHS-supplied infected blood. It was stated that the interim payments for Northern Ireland beneficiaries of the Infected Blood Payment Scheme will range between £4,000 and £8,000 per person, depending on individual circumstances.

41. On 27th January 2020, the groups met Oliver Dowden MP, the Minister for the Cabinet Office at that time and Nadine Dorries MP, a Junior Health Minister in Westminster. During the meeting, I again explained why Northern Irish contaminated blood victims so desperately required a financial uplift. The response we received from the various ministers we conducted meetings with was very positive.

42. Following the meeting, myself and my Northern Irish counterparts were informed by the Finance Minister for Northern Ireland Conor Murphy MLA that

the budget for 2019/2020 had already been agreed. Therefore, we would need to wait for change. The Northern Irish Government, however, were very quick to reassure us there would be further meetings to discuss this issue. These have been few and far between.

43. The Inquiry have been extremely helpful and facilitated a number of meetings with Ministers and Civil Servants in Westminster. HNI were given a seat at the table of many of these meetings thanks to the Inquiry.

44. I decided a united front would be more effective in addressing the avoidance approach of the DoH NI which we had encountered throughout the parity issue. I believed it made sense to strike up an alliance with the Haemophilia Society in late January/ February of 2020 and another group predominantly from the North West of NI (Friends and Families of Haemophilia Ni) who also became involved. I personally believed that the different haemophilia groups working together would more likely to create change rather than the politics and infighting that had taken place between different groups over the course of the years. Nigel and I personally knew [GRO-A] [GRO-A] and Paul Kirkpatrick the other spokespersons and respected them and their input for victims.

45. I have had two meetings with Robin Swann, the Minister for Health in Northern Ireland in early 2020. The first meeting took place on 13th February 2020 and the second, a remote meeting, was held on 23 March 2020. Email correspondence between my brother Nigel and I is **Exhibited before me at WITN2339033**. You will note from the Exhibit that attendees of the meeting were informed that money was being ring-fenced in Northern Ireland for parity and the minister confirmed three times to attendees that this should be recurrent now.

46. It was as a consequence of pressure leading up to and during the February 2020 meeting that DoH - under instruction from the minister- uplifted scheme payments to retrospectively provide parity for 2019 in line with English. We had lobbied hard for widows and subsequently a one-off £5000 payment was found

from funds to provide this. The minister also explained that the financial uplift would now be established and outlined a three stage strategy to ensure parity in all aspects of the scheme around an eclectic payment arrangement so that the highest financial support offered across the regions would be made available.

47. We had been fighting an uphill battle for many years. It needs to be remembered that Northern Ireland did not have an active government when the Inquiry started. Only since January of this year has the Assembly been up and running again. **Exhibited before me at WITN2339034** is a letter from Robin Swann MLA to Mervyn Storey MLA. In the letter Robin Swann discusses what was said in the meeting that took place with myself and fellow victims in February 2020. In the letter he reiterates that the payment uplift is non-recurrent and only applies to the period 2020/2021.

48. We then received a letter from the Department of Health in late March 2020 that confused us completely. We thought the letter would tell us that parity would be granted. The wording of the letter was quite frankly confusing and contradictory in light of our two meetings with the minister. **Exhibited at WITN2339035** is a copy of the undated letter. Myself, Nigel my brother and the other campaigners who had attended the meeting with the minister on 23rd March 2020 couldn't make head nor tail of what the letter meant. It went back on what we had discussed in a revisionist way undoing some of the important commitments. We had had such hope, Nigel's Judicial Review litigation (see below) was placed on hold for this. We had so many meetings in which it was said Northern Ireland would have parity with England.

49. We received a further response from the Minister for Health in Northern Ireland's office which was then immediately withdrawn. This was apparently a duplicate of the letter at **Exhibit WITN2339035**. We are still unclear what confusion led to this occurring.

50. On 24th March 2020, Robin Swann formally announced that Northern Ireland would receive the same infected blood payments as their English counterparts.

However, it was very disappointing to discover that the payment uplift was on a non-recurrent basis. The initial understanding we had from our two meetings with Minister Swann was that a further £1 million would be sourced and spent on victims in Northern Ireland and that other money, separate to parity funding, from the NI govt budget would be allocated to psychosocial services. The Minister continues to withhold the £1m for parity for 2020-2021 and has not requested any more funding to augment it in the last Executive budget monetary round in June 20 and subsequently in August 2020 despite assuring us that that was his intention in order to ensure the 'ideal' of proper financial parity. This appears therefore to be a chimera: perhaps desired but clearly out of reach.

51. A further announcement was made in early April 2020 by Mr Swann. He announced that widows and widowers would be awarded an additional £5,000 a year. I think a letter from Robin Swann MLA to two campaigners dated 5th May 2020, perfectly summarises the current situation in Northern Ireland. I refer you to the letter at **Exhibit WITN2339036**. In the letter Mr Swann states that due to the current Covid-19 pandemic parity has fallen down the agenda.

52. Unfortunately, the focus of the Northern Irish Assembly has turned to the covid-19 pandemic and its deadly consequences. The pandemic has diverted attention from the Inquiry, and it has felt like our calls for recurrent parity have become background noise in the midst of chaos. I also wonder whether the pandemic has aided the DoH to obfuscate the situation further with delays on responses to FOI requests and any response from the minister to my 29 May letter for clarification on his position. Although this has not stopped me from pursuing this issue and I refuse to give up.

53. On 29th May in my capacity as Chair of HNI, I wrote to our current Paymaster General, Penny Mordaunt MP. In my letter **Exhibited before me at WITN2339037**, I state my grievances regarding the current situation in Northern Ireland and request she considers the situation for victims in Northern Ireland.

54. Following my letter to Penny Mordaunt MP, in May 2020, I again wrote to Robin Swann MLA. In my letter dated 29th May and **Exhibited before me at WITN2339038**, I ask the minister 4 questions;

"1. I would like clarification on why a precedent which was set has not been established.

I do appreciate your position, or rather ambition, to ensure 'proper' parity with England and the other regions. However, this appears purely aspirational when you do not have the funds to meet that stated objective. We struggle to understand what benefit there is for the scheme recipients in aspiring to 'find parity' across the scheme when there is clearly insufficient money to achieve that.

2. I would like clarification on why the money from the Department of Finance (ringfenced to provide achievable parity is still being withheld).

Why can your officials not continue to strive with this ambition while the uplift is implemented in the meantime (as set out in your precedented solution)? I have some concerns regarding the progress of this ambition. Your stated objective appears to be one based on a correspondence I had with your Permanent Secretary Mr Richard Pengelly, prior to the reconvening of the Assembly (we corresponded on 15 August 2019 and a copy is attached).

3. I would like to know what progress has been made on the establishment of parity outlined by Mr Pengelly in his August letter to me prior to you taking post.

You see Minister, there appears to be very little evidence of any progress while the Public Inquiry trundles on through the pandemic to its inevitable end. Yet, we continue to see prevarication and semantics obstructing actual progress. Where is the accountability in a process that seems to lack the finances to make it possible.

4. I would like to know whether you intend to withhold any parity uplift unless you can achieve a 'complete' parity arrangement. As you know this doesn't exist across any of the regions after two years of verbal 'wishing' and aspiration from Cabinet and devolved institutions.

Minister, I do appreciate all that you have done and perhaps the disappointment and frustration of the scheme recipients hinges on the confidence we have had since you took post. However, we are seasoned in facing disappointment and prevarication and consequently, I urge you to do what is currently achievable while still aspiring through your officials for something more."

55. I have not yet received a response from the Minister. However, I emailed the Minister's private secretary on the 17th August 2020 and asked again for an "honest and considered response". I have **Exhibited before me at WITN2339039** a copy of my email correspondence with Robin Swann's Private Secretary. You will probably note from my tone in the email that I have become pessimistic about the response I will eventually receive from the Minister. I am firmly of the opinion that DoH have obfuscated the process and over a long period of time have failed to make any genuine progress to finding payment scheme parity. I believe my letter and subsequent FOIs will confirm that little or nothing has actually been done and the litany of promises really amount to a cynical postponement of any real commitment to meeting Sir Brian's original request.
56. Myself, Chair of Haemophilia Scotland Bill Wright and Governor of the Scottish Infected Blood Forum, John Rice wrote to Paymaster General, Penny Mordaunt MP. In the letter dated 2nd June 2020, **Exhibited before me at WITN2339040** we urge Ms Mordaunt to engage in dialogue with ministers of the devolved nations about parity.
57. On the 11th June 2020 I made a freedom of information request to Northern Ireland's Department of Health regarding information on the infected blood payment scheme and progress of parity. A day later I received an acknowledgement email from Northern Ireland's Department of Health acknowledging my request. Some days after the stated 20-day response time, I received an email from the Department of Health apologising for the delay and assuring me I would receive a response by mid-August.
58. It is now late August 2020 and I am yet to receive the information I requested in my email to the Department of Health on 11th June 2020. As result of the delay I sent a complaint email to the Department of Health on 20th August 2020. In my complaint email **Exhibited before me at WITN2339041**, I set out the reasons for making the complaint. I state that "I do not believe it is reasonable or acceptable in the current circumstances where I have been assured there is a team dedicated within the department to deal with Infected Blood Inquiry

issues". I still await a confirmation of receipt. Frankly, it is now clear that the DoH has little intention of taking us seriously and our right to expect any serious approach from the DoH has been seriously undermined. Where is the accountability? Where will it be when the Public Inquiry concludes its recommendations?

59. I also made an FOI request to the DoH on 20th August 2020. This was for further clarifications around the DoH dedicated team working on the infected blood inquiry issues. **Exhibited before me at WITN2339042** is a copy of my email to the DoH. I ask them to confirm/provide the following:

"The dates that DoH has requested additional funding from the Executive's quarterly budgetary monitoring rounds to support an increase in budget for the Infected Blood payment scheme since 1st January 2019 until 20 August 2020

The planned budget for infected blood payments managed by BSO for the years 2018, 2019, 2020, 2021

There is a dedicated team dealing with infected blood issues and the Infected Blood Inquiry and the number of staff and total monthly working time carried out on infected blood issues for this team between December 2019 and August 2020 by month"

60. I now seriously have doubts that effective campaigning and good advocacy will eventually bring about change. I see the DoH and much of the political machinery of government as monolithic, obdurate and not genuinely interested or committed to resolving simple problems effectively. HNI has tried to be progressive. We are not targeting clinicians, the Inquiry are. As a charity we are clear of our objective and what causes we need to be fighting for. The same principle applies in respect of the pharmaceutical companies. HNI are relying on the public inquiry to see that the government did not take notice and action of their misconduct. It would not make sense for a charity like HNI with a small turnover to take on multi-billion-dollar pharmaceutical companies. I see the Public Inquiry as the last hope of the contaminated community. Government and in Northern Ireland, DoH, are not our friend. The machinery which drives

progress in the parity process has by now been exposed as seriously wanting or wilfully obdurate.

Section 4: Research and Investigation

1. As I have set out earlier in my statement, HNI is a currently a small charity. We are growing and expanding, however it will be a short while before we have the funds required to carry out research regarding haemophilia.
2. Our Scottish counterparts at Haemophilia Scotland have a substantial annual turnover. At HNI we are ambitious and aim to grow and be as big as Haemophilia Scotland but for the time being the work that is carried out by HNI is carried out in good faith.
3. HNI has more so been focussed on lobbying for parity in Northern Ireland with this being the main objective for us. We aim to be engaged in more research in the not so distant future now that we have established ourselves.
4. As I have mentioned above HNI was involved in the publication of a book for young haemophiliacs. The authors of this book were creating a book in order to inform and educate, we had a role in their research when they created the book.

Section 5: Individual campaigning activities

1. This section is covered in section 3.

Section 6: Complaints to Police, Ombudsman or Regulatory Authorities

1. I have not made any complains and I am not aware of any of the members of HNI having made such complaints against public bodies. Complaints should be made when all other options have been exhausted. In regard to the contaminated blood scandal I do not believe we have concluded our investigation of this, therefore no complaints have been made.
2. I believe the treatment that many haemophiliacs received in the 1970s and 1980s was given in good faith. Although, I now know from evidence presented

to the Inquiry that some clinicians were aware that they were giving some of their patients contaminated products.

Section 7: Litigation

1. HNI has not been involved in any litigation.
2. The litigation that is currently going on in regard to the public Inquiry, the Group Litigation Order ('GLO') has been put on hold pending the Inquiry. I think that if victims and their families believe after the Inquiry they are not satisfied with the Chair's findings then litigation such as the GLO should be considered.
3. When England were awarded their financial uplift in 2019, we knew parity was now essential. During the Infected Blood Inquiry witness hearings in Belfast myself and Nigel spoke with our legal representatives about next steps we could take in terms of parity. Our legal representatives provided us with a contact in Northern Ireland. In August 2019, a few months after the Infected Blood Inquiry witness hearings in Belfast we contacted solicitor Laura Banks of Francis, Hanna & Co.
4. During the meeting with Laura Banks, we discussed the possibility of pursuing litigation in regards to victims payments in Northern Ireland. Our goal was to obtain disparity of payments made to individuals in Northern Ireland infected with contaminated blood products who received considerably less than their counterparts in England and Scotland.
5. In response to a letter sent by Nigel's solicitor, the Department of Health responded in a letter dated 4th November 2019.. In the letter they ask Nigel to withdraw his instructions to proceed with the Judicial Review as they are working to reform the current scheme in Northern Ireland. The letter however does not provide any assurance that the scheme will be reformed permanently and thus Nigel chose to proceed with the litigation.
6. In Nigel's second meeting with Laura it was explored as to whether or not we would be able to source someone eligible for Legal Aid. Luckily after going

through the strict Legal Aid criteria in on 3rd December 2019 it was concluded that Nigel would be eligible for it himself. In the weeks that followed, Nigel provided a witness statement and his solicitor, Laura and proceedings were issued.

7. Laura then wrote to the Department of Health and they had 21 days to respond. The Department of Health responded outside of the 21-day deadline. Proceedings then went before a judge in January of this year. In the time between October and January, Nigel and myself had been attending a number of meetings with Northern Ireland's Health Committee Members. I was asked to provide a witness statement to in support of Nigel's case, a copy of which is **Exhibited before me at WITN2339043**. In the statement I discuss the struggles Nigel myself and all other infected blood victims in Northern Ireland have experienced. At the end of my statement I make comparisons with the English Infected Blood Support scheme following a freedom of information request I made.
8. On 30th April 2019, it was announced that England's infected blood victims would receive a financial uplift of £45 million. In Northern Ireland meanwhile only 99 infected blood victims and their family are in receipt of payments from BSO without hope of proper parity. It really seems that the DoH is determined to obfuscate the parity issue as a matter of principle. They would rather pay the costs of a legal case than follow the example given in England.
9. At this point, Nigel was being asked by the solicitor to go ahead with proceedings whilst the negotiations were taking place during meetings with Northern Ireland politicians. At the same time a judge requested that litigation proceedings should be placed on hold whilst political negotiations took place.
10. After due consideration and a growing awareness of the bad faith of the DoH Nigel has decided to proceed with the judicial review. We are currently waiting to receive the judge's decision on whether this should proceed to a court hearing.

Section 8: Other Inquiries

1. I have not been a participant in any of the Inquiries that have taken place in relation to the blood scandal.
2. HNI did not exist when the Archer and Lyndsey Inquiry were taking place. The Penrose Inquiry was a Scottish focussed inquiry, therefore we did not participate in Penrose.
3. After Lord Archer published his report I thought the Inquiry had not fully served its purpose but did not have teeth.

Section 9: Haemophilia Society

1. I was a member of the Haemophilia Society for many years before HNI was established. My brother Nigel was a trustee of the Haemophilia Society and was more involved than myself. Nigel attended many meetings across the British Isles with the Haemophilia Society. A number of HNI members were also part of the Haemophilia Society.
2. In 2018, I had a meeting with the GRO-A the UK Haemophilia Society GRO-A GRO-A During the meeting I set out a number of grievances people in NI had with the society and this has since led to us having a better working relationship. GRO-A has been a breath of fresh air and I have definitely seen a change in the direction of the society GRO-A
3. The purpose of HNI's relationship with the Haemophilia Society was primarily focussed on how we can work together to ensure the best possible outcome for victims and their families in NI and to share our common interests in supporting families dealing with bleeding disorders and infected blood.
4. Any bad feeling that I once had for the Haemophilia Society has now gone including the feelings expressed in Section 2. We share the same objective which is achieving justice for victims and helping each other out along the way.

Section 10: Trusts and Schemes

1. The Business Services Organisation (BSO) is the name of the body that is in charge of payments to contaminated blood victims in Northern Ireland.
2. I am of the opinion that BSO is run sufficiently well by the administrator. I have no problem with the scheme itself, what I have had a problem with is the Northern Irish Government who have adopted a high-handed approach to offering sufficient assistance to victims.

Conclusion

1. Upon reflection, working with the British Government (Cabinet Office sponsors of the Inquiry) and the NI Executive and Department of Health NI has been and remains a stressful and difficult experience. I have received many assurances of support and commitment from ministers, letters of assurance from Prime Ministers and written and verbal assurances of progress from civil servants. In summary, this has not been matched by action. The gift of those who have the power and influence to make right the wrongs of the past has been squandered so that there is no consistency in the following through of hollow commitments. I now regard both the language and behaviour of political leaders and civil servants, capable of doing the right thing, with great scepticism. I do not believe there is a will to do the right thing or make good the commitments and promises that have been showered on the infected blood community. There are no champions in government who care sufficiently to address the wrongs of the past and present. Campaigners for the infected blood community are no better than prophets without honour in their own land. Rather than being able to work with our leaders in the devolved nations we are shunned and left to feel like a nuisance that will not go away. Our determination and belief in seeing right being done has blinded us to the hard reality that we don't really matter anymore than those victims of the infected blood scandal who have already died.

Statement of Truth

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

Signed.

GRO-C

Dated.. 25/8/2020