Witness Name: Lynne Kelly
Statement No:WITN3988001
Exhibits:WITN3988002-WITN3988093
Dated: 30 July 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MRS LYNNE KELLY

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

I, Lynne Kelly, will say as follows:-

Section 1 Introduction

1) Please state your name, address and date of birth

1. My name is Lynne Kelly. I live at GRO-C Cardiff GRO-C and my date of birth is GRO-C 1962. I am currently Chair of Haemophilia Wales which is a charity, registered on 23 October 2014 under registration number 1158941.

Section 2 Organisations involved in campaigning activities

1) Describe your involvement in setting up:

a) Any campaigning organisation whose aims and activities are relevant to the Inquiry's Terms of Reference

Haemophilia Wales

2003-2010 - Committee Member

2014 to date - Chair

1. Haemophilia Wales was established as an independent charity in 2003 and provides information support and advocacy to over 300 members in Wales. It replaced the South Wales Haemophilia Group which was established in 1967.

2. We are affected unpaid volunteers independent of the UK Haemophilia Society. Our Trustees and members have been campaigning for justice from the outset of the disaster when the first haemophiliac in the UK to contract the HIV virus was diagnosed in Cardiff in 1983.

3. As of the date of this statement six of our original committee members have died as a result of contaminated blood. We estimate there have been over 100 deaths in Wales as a result of contaminated blood out of approximately 300 people who were infected through blood or blood products.

4. As a charity we represent and campaign equally on behalf of haemophilia and transfusion patients, families and bereaved families affected by contaminated blood.

5. An important principle of the Welsh campaign was there was no distinction between 'groups' whether they were affected by transfusion or haemophilia care, or were HIV or hepatitis C infected or a family member or bereaved family member. The fact remained that they or a family member attended hospital and their lives changed forever as a consequence.

The Cross Party Group (CPG) - Welsh Assembly

Cross Party Group Haemophilia and Contaminated Blood at the Welsh Assembly Chair 2011 onwards

6. Following representations to the Welsh Assembly about the issues affecting haemophiliacs, the Cross Party Group (CPG) on Haemophilia and Contaminated Blood was formed in 2011 at the Welsh Assembly by my Assembly Member Julie Morgan. The purpose of the group is to raise awareness of haemophilia and the effects of contaminated blood. Julie Morgan was the original Chair of the group and has been involved in the health care issues surrounding the affected community since the 1990s, both as an MP at Westminster and as an Assembly Member. Julie attended an All Party Parliamentary Group (APPG) meeting with Michael

Imperato of Watkins & Gunn and I on 4 September 2017 to present on the importance of a Judge led public inquiry.

7. In 2019 Julie was promoted to Junior Health Minister at the Welsh Assembly and Mick Antoniw AM now chairs the CPG. Mick is the Assembly Member for Pontypridd and has been involved in the group since 2011 when he was asked to join to support his constituents who were infected with contaminated blood. The CPG meetings are large and patients, families and bereaved families are encouraged to attend and actively engage with members. Welsh Assembly Members continue to be a strong political voice in the continuing search for truth and justice for the affected community. Since May 2020 Assembly Members (AMs) are known as Members of the Senedd which is the Welsh Parliament (MSs).

8. Exhibited before me at **Exhibit WITN3988002** is a letter dated 27 November 2013 from Mark Drakeford, Welsh Health Minister, to Julie Morgan AM regarding the absence of Consultant Hepatology opinion in Cardiff. The letter also includes information about lack of financial support, insurance and mortgage protection for Welsh infected blood individuals and families and calls for a Welsh public inquiry.

9. Exhibited before me at **Exhibit WITN3988003** is a letter dated 20 December 2016 from Vaughan Gething, Welsh Health Minister, to Jeremy Hunt, Secretary of State for Health, regarding consultations in Wales on financial support and the strength of feeling in Wales in favour of UK wide inquiry into contaminated blood.

All Party Parliamentary Group (APPG) – Westminster

APPG Haemophilia and Contaminated Blood Member at Westminster 2011 onwards

10. From 2009 I contacted everyone known to me affected by contaminated blood including patients and beneficiaries of the various schemes and also bereaved families who would not be registered as a scheme beneficiary or patient. I encouraged them to meet with their MPs to raise awareness of contaminated blood and the lack of treatment and support. The inaugural meeting of the APPG was on 17 October 2012 and I attended with my then MP Jonathan Evans. Paul Goggins MP had affected constituents in Wythenshawe, which was previously Lord Alf Morris' constituency, both actively campaigned on behalf of the contaminated blood community until they died. Alistair Burt who, as an MP, campaigned on behalf of his constituent GRO-A was recently promoted to Minister in the Government and whilst he could no longer actively campaign he continued try to exert some influence in the APPG.

11. Welsh MPs who joined the APPG did so on behalf of their constituents in Wales to help address the issues affecting them. In contrast to the CPG meetings in Wales, the APPG meetings held in Westminster are usually small meetings, chaired by Diana Johnson and Peter Bottomley, attending together with representatives of English campaigning groups, with the Haemophilia Society providing the Secretariat.

12. Diana Johnson takes her lead from her constituent Glenn Wilkinson and the Haemophilia Society and their aims do not always align with other campaigning groups regarding the public inquiry or support systems. Initially they did not support our calls for a Judge led inquiry and favoured a panel led by the Bishop of Liverpool. There was a focus on victims who were described by the support schemes as 'Stage 1's' and a lack of emphasis on HIV victims and bereaved families. There were disagreements between Haemophilia Wales and the Haemophilia Society relating to the Haemophilia Society's lack of focus on contaminated blood and their unwillingness to recognise Haemophilia Wales as a charity. Haemophilia Wales did not support the Haemophilia Society's proposal to the Government on financial support in 2016.

13. Exhibited before me at **Exhibit WITN3988004** is an email I sent to GRO-A Chair of the Haemophilia Society, in September 2019, which sets out Haemophilia Wales' concern about the Haemophilia Society launching an inquiry into access to new treatments which was proposed to be sponsored by a pharmaceutical company. We also raised concerns about the appropriateness of the APPG being involved in this process. In Wales, if issues regarding access to treatments are experienced and cannot be resolved by the Haemophilia Centre, they can be raised by the patient themselves and or Haemophilia Wales at the All Wales Advisory Group on Inherited Bleeding Disorders. If still unresolved the matter can then be raised at the CPG. This approach has always been encouraged by the Chairs of the CPG and patients have felt it is a safe environment to highlight issues affecting them and it has proved to be an environment which gives politicians and clinicians direct feedback of patient experiences.

14. Haemophilia Wales actively campaigned for a Judge led public inquiry rather than a 'Hillsborough' style panel and we lobbied hard to ensure that Welsh Government voted unanimously in favour of a Judge led public inquiry in January 2017. We also lobbied to ensure that a public inquiry into contaminated blood was included in the Welsh Labour Party Manifesto and the National Labour Party Manifesto.

15. A Judge led public inquiry, however, was not the view being presented by the APPG to Westminster by Diana Johnson who was very strongly influenced by Glenn Wilkinson and

supported in her view by Peter Bottomley. All campaigning groups, including Haemophilia Wales, wrote to the APPG. Exhibited before me at **Exhibit WITN3988005** is a copy of that letter dated 6 November 2017. The letter expresses their concerns about the direction of the APPG and its failure to reflect the views of the main campaigning groups who wanted a Judge led inquiry. Haemophilia Scotland did not support a public inquiry and particularly did not support a Judge led inquiry.

16. Ultimately Julie Morgan AM, as Chair of the CPG, refused to sign the APPG statement to the Prime Minister which stated that a panel would be preferable to a Judge led inquiry and subsequently the Welsh Government took the same action. The letter written by Julie Morgan AM to Diana Johnson MP dated 17 October 2017 is exhibited before me at **Exhibit WITN3988006**. It was an important step in the process as all of the main campaigning groups knew that without a formally structured public inquiry with the appropriate terms of reference and the power to compel witnesses, the necessary evidence would not have been made available.

17. I have attended many APPG meetings including an APPG meeting with Julie Morgan and Michael Imperato on 4 September 2017 to present on the importance of a Judge led public inquiry. I continued to raise our concerns that the APPG was evolving into a lobby group exclusively for a Hillsborough type inquiry with a panel and a focus on Hepatitis C and Special Category Mechanisms for 'Stage 1s'. Haemophilia Wales made it clear that this direction no longer represented the wishes of the community as a whole and as a result Haemophilia Wales were subsequently excluded from the APPG circulation list and future meetings.

18. There were further disagreements in 2019 when the APPG launched an inquiry into Haemophilia treatments and misinformed Welsh MPs that there was a problem with Welsh patients accessing new longer lasting haemophilia treatments. This was not and is not the case in Wales as Haemophilia Clinicians are free to prescribe the new treatments which is not the case in England. This disinformation, or failure to understand the systems being developed in Wales, was a cause of concern for the patient groups and a clear indication of the lack of understanding of the issues in providing improved care across the care system that The Haemophilia Society held.

19. These disagreements resulted in Haemophilia Wales being excluded from the circulation list until the APPG was reformed on 11 February 2020 and Welsh MPs Jo Stevens and Jessica Morden became Vice Chairs. This change will ensure that Welsh constituents' voices continue to be heard at Westminster and the direction of travel of the Cross Party Group on Haemophilia and Contaminated Blood will now be considered in the APPG discussions.

b) Any organisations offering support or assistance to people who are infected or affected

20. I am currently involved with two groups who offer support or assistance to people who are infected or affected. These are Haemophilia Wales and the Cross Party Group on Haemophilia and Contaminated Blood. I was, but am no longer, on the Board of the Wales Infected Blood Support Scheme.

21. From 1989 to 2003 I was a member of the South Wales Haemophilia Group.

c) State when each organisation was set up and what prompted or led to its establishment

22. **1967-2003** Original South Wales Haemophilia Group
I became a committee member of South Wales Haemophilia Group GRO-C GRO-C in 1989.

23. **June 1999** The South Wales Haemophilia Group
This group was re-formed with a formal committee: Gareth Lewis as Chair, David Morgan as Vice Chair, Jan Wallace as Secretary and Ian Tumelty as Treasurer. The committee members were GRO-A GRO-A GRO-A Bev Tumelty GRO-A and GRO-A GRO-A and GRO-A and myself. Meetings were arranged with Julie Morgan MP to gain support for a new Comprehensive Care Haemophilia Centre at Cardiff and raising funds for the group.

24. **29 April 2003** Haemophilia Wales
David Morgan (Chair) and Jan Wallace (Secretary) stood down and Haydn Lewis was voted in as Secretary. With the subsequent death of David Morgan and Haydn and Gareth Lewis Haemophilia Wales became in-active.

25. **January 2011** Haemophilia Society
I was a Trustee of the Haemophilia Society from January 2011 until June 2014 when I tendered my resignation due to the in action of the Haemophilia Society in addressing the concerns of the affected community and the general lack of clear direction and leadership. Exhibited before me at **Exhibit WITN3988007** is a copy of my resignation letter.

26. **23 October 2014** Haemophilia Wales
Haemophilia Wales was reconstituted with a new board of trustees and Chair and is currently engaged as described above.

27. **2011** All Party Group Haemophilia and Contaminated Blood at Westminster.

28. **2011** Cross Party Group Haemophilia and Contaminated Blood at the Welsh Assembly.

3) Identify any positions you have held within the organisations, the dates that you held the positions and your role and responsibilities in that capacity

1. From 1989 onwards I was a member of the South Wales Haemophilia Group and my role involved fundraising, networking with new families and generally supporting families with haemophilia.

2. In 1996-1997 I was involved in a successful lobbying campaign, supported by Julie Morgan MP, for funding for safe non plasma derived Recombinant Factor 8 and 9 which was agreed for Wales as a result.

3. On 23 October 2014 I re-established Haemophilia Wales and became its Chair. The current Haemophilia Wales committee members and Trustees are Nigel Miller, GRO-A, GRO-A and GRO-A David Thomas, Tony and Pat Summers, GRO-A, GRO-A, Mike O'Driscoll and one Trustee who is anonymous.

4. The team remain as committed as their predecessors were to achieving the goals set out by the South Wales Haemophilia Group, Birchgrove Wales and the founding members of Haemophilia Wales.

4) Describe the main activities of the organisations and any outcomes achieved by the organisation over the years since its establishment

General Fundraising

1989 to 2003 - South Wales Haemophilia Group fundraising activities

1. GRO-C I became friends with many haemophiliacs infected with HIV and later hepatitis C, their families and bereaved families. I organised car boot sales, street collections, coffee mornings, children and families' events, BBQs, mothers meetings and networking events. These events raised funds to support the wide network of competing interests which come with an organisation facing the history of contaminated blood and the ongoing support for families with haemophilia. This included support for some recently diagnosed families and for some this would have been the first

experience of haemophilia in their families and for others their involvement with the community was following the death of a loved one.

Arthur Bloom

2. The team additionally organised the Arthur Bloom Memorial evening at The Park Hotel Cardiff with Gareth Lewis and Paul Jenkins to raise funds for the commissioning of a Bronze bust of Professor Arthur Bloom. This was an important milestone as Professor Arthur Bloom was held in high regard by the haemophilia community for the care he provided over generations in the centre.

3. The point that Professor Bloom was held in high regard by the haemophilia community has been over shadowed, if not lost entirely, by the recent social media coverage and the threatened forced removal of the bust by some English campaigners. Whilst many individuals and families in Wales remain shocked by the recent evidence of the actions of clinicians, they however wanted to wait for the outcome of the Inquiry before any action was taken. The Bronze bust has now been removed by The Centre staff to avoid further upset and problems within the community.

New Drugs Treatment – non plasma derived Factor 8 and 9

4. Haemophilia Wales consistently contacted MPs to continue to lobby for the introduction of Recombinant Factor 8 which was introduced in Wales in 1997 a goal achieved earlier than in England due to a lack of lobbying on the part of the Haemophilia Society.

The new Haemophilia Centre

5. Prior to the opening of the University Hospital of Wales (UHW) in 1971 haemophilia patients had been treated at Cardiff Royal Infirmary by Dr Bloom. The Haemophilia Centre in UHW while small, consisting of a waiting room and one treatment room, was further scaled back due to hospital cut-backs and subsequently moved to shared space in Malignant Haematology. This saw very poorly cancer patients undergoing chemotherapy treatments alongside noisy, stressed children receiving haemophilia treatment. Patients and staff were upset by the new arrangement as it undermined the whole concept of comprehensive care for haemophilia, which was developed in the 1960s, the concept being to treat the affected person and family through continuous supervision of all medical and psychosocial aspects of their bleeding disorders. As a patient group we worked with Haemophilia Clinicians to highlight the issues affecting clinical care resulting from the substandard accommodation. Myself and others in the South Wales Haemophilia Group contacted our MPs and various meetings were arranged with patients, politicians, clinicians and Health Board officials. We

had a clear vision of what was needed in our new Haemophilia Centre and this was supported by the clinicians. The new Haemophilia Centre was subsequently established in 1999.

Haemophilia Wales

6. Haemophilia Wales has been instrumental in maintaining pressure on central and devolved Governments to improve the standards of haemophilia care across Wales. Some of the activities of Haemophilia Wales and outcomes achieved over the years include:

a) The establishment of the Arthur Bloom Comprehensive Care Haemophilia Centre in Cardiff;

b) The introduction of Recombinant Factor 8 and Factor 9 in Wales;

c) Dedicated parking spaces for haemostasis patients;

d) Ambulance letters for haemophilia patients to ensure they are taken to a Haemophilia Centre and not their local hospital;

e) The successful lobbying of the Welsh Health Ministers; Edwina Hart, Lesley Griffiths and Dr Chris Jones, Chief Medical Officer in Wales, leading to a review into haemophilia care and improved payments in Wales;

f) The Back Bench Business Debate on Contaminated Blood (14 October 2010) initiated by Owen Smith MP for Pontypridd;

g) Through our work as a member of the Ministerial Task and Finish Group Review into Haemophilia Care in Wales 2011, the appointment of a Consultant Hepatologist at the University Hospital of Wales in Cardiff (UHW);

h) Specialist haemophilia physiotherapy and psychological support throughout Wales;

i) Dedicated welfare and benefits advice for everyone affected by contaminated blood;

j) A supporting organisation to the Cross Party Group on Haemophilia and Contaminated Blood at the Welsh Assembly chaired by Julie Morgan AM;

k) As a member of the All Wales Advisory Group on Inherited Bleeding Disorders, chairing the Welsh Health Specialised Services Commission (WHSCC) with haemophilia doctors, nurses, physiotherapists, haemophilia psychology and social worker support and patient representatives from all over Wales;

l) Haemophilia Wales has been instrumental in securing:

- Four haemophilia psychologists to serve the patients at the Cardiff, Swansea and Bangor Haemophilia Centres;

- Three haemophilia physiotherapists to serve the patients at the Cardiff, Swansea and Bangor Haemophilia Centres;

- One haematologist to serve the patients at Swansea;

- One hepatologist to serve the patients at Cardiff; and

- Four Fibroscan machines to allow monitoring of fibrosis for haemophilia patients with hepatitis C.

m) Haemophilia Wales has also supported and championed the Interim Commissioning Policy for Sofosbuvir - the Interferon free hepatitis C treatment for the severely ill;

n) Improvements in Social Work support in Wales;

o) As a result of lobbying by Haemophilia Wales members and the Cross Party Group on Haemophilia and Contaminated Blood, £13.8 million was ring fenced by Welsh Government in September 2015 for hepatitis C treatments;

p) Wales is leading the way eliminating hepatitis C. Interferon free hepatitis C treatments have been rolled out across Wales for everyone with hepatitis C. Due to our continued work, all haemophiliacs and infected blood patients in Wales have now been treated with hepatitis C treatments ahead of England. There is currently no waiting list for anyone needing treatment for hepatitis C in Wales.

7. Haemophilia Wales has been instrumental in maintaining pressure on central and devolved Governments for a public inquiry and adequate financial support for victims and their families:

a) The continued lobbying of both Assembly Members and MPs for truth and justice for haemophiliacs infected with HIV and hepatitis C as a result of contaminated blood products;

b) Haemophilia Wales Response to Department of Health Proposals and Consultation Infected Blood which is exhibited before me at **Exhibit WITN3988008.**

c) 7 February 2016: Carwyn Jones 1st Minister, Welsh Assembly wrote to Jeremy Hunt regarding the shortcomings of new proposals on infected blood support in England.

d) 12 April 2016: A Contaminated Blood Debate and Protest was held at Parliament and attended by Haemophilia Wales and Welsh MPs.

e) 12 April 2016: Myself and Haemophilia Wales Trustees met with Alun Cairns, Secretary State for Wales, and my then MP Craig Williams at the Welsh Office to discuss implications for Wales. Alun Cairns had not been briefed on the position in Wales and advised that people would receive payments depending on where they lived in the UK.

f) 6 July 2016: Haemophilia Wales met with Welsh Health Minister, Vaughan Gething, to highlight that people in Wales would be worse off under the new English scheme. Exhibited before me at **Exhibit WITN3988009** is the response from Vaughan Gething dated August 2016 which followed the 6 July meeting about responsibility for devolved schemes and the Spending Review 2020-2021. We have consistently lobbied Westminster and the Welsh Government about the lack of financial support which has been used as a political football since devolution in 1999.

g) Hardship Grants: As a result of difficulties accessing grants from the Macfarlane and Skipton Trusts and the Haemophilia Society, Haemophilia Wales recognised that people often need small sums of money, up to £250, which could not be accessed immediately due to the bureaucracy and inflexibility of the trusts. These sums cover a variety of needs from hotel accommodation while patients were being treated over long periods in hospital, buying essential items for long hospital stays and transport costs for hospital visits and for bonds for rented accommodation. The grants were established as Haemophilia Wales was contacted by the Social workers in Cardiff and individuals affected by contaminated blood as they had been refused support from the Haemophilia Society 's Tanner Fund.

h) The Tanner Fund had been set up by Reverend Alan Tanner, former Chair of the Haemophilia Society who lost his son to HIV and organised and conducted the Annual Thanksgiving service in memory of those who had died. It was clear to Haemophilia Wales that there was an unmet need to provide small grants quickly without a lengthy application process and this has proved to be very helpful to patients and families.

i) In early 2016 a consultation had begun in respect of a new scheme for infected blood support. It was in respect of this that we sought legal advice. We approached a number of well know law firms in Cardiff but they were not sympathetic or wanted to charge high legal fees. Eventually, in March 2016, we were referred to Michael Imperato at Watkins & Gunn who was prepared to listen and help and to act pro bono. Michael advised us that the consultation only applied to England even though we had been told by the Welsh Government that it was UK wide. Michael proved to be correct.

j) In July 2016 an England-only scheme was announced for Infected Blood Support. On 29 July 2016 Haemophilia Wales challenged the Welsh Government to demand a Wales specific consultation to ensure that affected people in Wales could voice their concerns.

k) October 2016: Haemophilia Wales met with Vaughan Gething. A 12 week consultation period was agreed with the English scheme adopted as an interim measure.

l) December 2016: Consultation and Workshops in North Wales.

m) January 2017: Consultation and Workshops in South Wales.

n) Having successfully established that there had to be a Welsh consultation, we discussed with Michael Imperato whether we could press for a full public inquiry into the historic infected blood scandal. Michael and his legal team began to look into the issue and we had a number of meetings with Michael and Barristers. Michael obtained Legal Aid to consider a possible Judicial Review (JR) challenge to the Government's reluctance to consider such an inquiry.

o) 25 January 2017: The Welsh Government voted unanimously in favour of a UK wide public inquiry into contaminated blood.

p) 30 March 2017: A new Wales Infected Blood Support Scheme (WIBSS) was established at Velindre Hospital Cardiff.

q) 17 May 2017: Haemophilia Wales and the Cross Party Group ensured that Welsh Labour gave a commitment to hold a public inquiry into contaminated blood, the commitment was included in the Labour Party Manifesto.

r) 21 June 2017: Truth and Justice Protest at the Department of Health attended by Haemophilia Wales, Welsh MPs and victims. Letter delivered to Number 10 by Bronwen Morgan, granddaughter of David Morgan, ex Chair of Haemophilia Wales, who was campaigning for justice as her grandfather had done. A film was commissioned by S4C and ITV outlining her journey to London, the subsequent protest and the delivery of the letter to No 10, alongside other campaigners and Diana Johnson MP demanding a public inquiry. In Theresa May's opening speech, Albert Owen Anglesey MP intervenes to ask for a public inquiry.

s) At the end of June 2017 our lawyer Michael Imperato sent a Judicial Review letter before action to the Westminster Government saying that if they did not agree to a public inquiry within 14 days, Judicial Review proceedings would be issued.

t) 11 July 2017: Public inquiry into contaminated blood announced by Theresa May. This was the 14th day after the letter before action mentioned above. Therefore, I believe Haemophilia Wales and our lawyer, Michael Imperato, played a key role, and an unheralded role, in the establishment of the Inquiry.

u) 4 September 2017: I attended the APPG meeting with Julie Morgan AM and Chair of the CPG on Haemophilia and Contaminated Blood and Michael Imperato to present on the importance of a Judge led public inquiry as opposed to a Hillsborough type inquiry or a panel. It was clear at this meeting that there was a divergence of opinion led by Diane Johnston MP who seemed determined not to have a judge led inquiry. Michael spoke specifically on this point to the meeting.

v) 12 September 2017: I attended the Bishop of Liverpool meeting which had been arranged by Diana Johnson MP.

w) 28 September 2017: The Cross Party Group on Haemophilia and Contaminated Blood writes to APPG asking them to support Judge led chair.

x) January 2018: Justice Brian Langstaff was announced as chair of the Infected Blood Inquiry.

y) 14 March 2018: Meeting with Sir Brian Langstaff at the High Court. Sir Brian was taking the views of victims in respect of the Terms of Reference of the Inquiry. I attended with Michael Imperato and we met with other campaigners from other groups.

z) 26 April 2018: Haemophilia Wales and the Cross-Party Group in the Welsh Assembly on Haemophilia and Contaminated Blood responded to the consultation on the Infected Blood Inquiry's Terms of Reference. A copy of that response is exhibited before me at **Exhibit WITN3988010.**

aa) On 5 September 2018 Haemophilia Wales met with Alex Scott Cardiff and Vale Medical Records and Professor Peter Collins to agree a national coordinated approach for Wales for medical record retrieval. A single point of contact and an 'all Wales' approach was agreed with NHS Wales and Alex Scott was the lead at Cardiff and Vale. A flyer was produced which is Exhibited before me at **Exhibit WITN3988011.**

bb) On 17 September 2018 Haemophilia Wales wrote to all CEOs of Welsh Health Boards asking for a concerted approach for people accessing medical records and replies were received from all Health Boards agreeing to this.

8. Haemophilia Wales has a good working relationship with Birchgrove Group, Tainted Blood, Factor 8 Campaign, Positive Women, Manor House Group, Fatherless Generation, Forgotten Few, and Haemophilia Scotland.

Section 3 Involvement in committees and/or working groups

5) Set out your membership, past or present of any committees or working groups relevant to the Inquiry's Terms of Reference

1. I have been involved in the following committees and working groups:

a) Ministerial Task and Finish Group to Review Haemophilia Services in Wales 2011
b) All Wales Advisory Group on Inherited Bleeding Disorders 2011- to date
c) The Haemophilia Alliance 2011 to 2014
d) Rare Diseases Group to develop and refine UK Strategy for Rare Diseases 2013
e) Haemophilia Society November 2011-June 2014
f) Rare Diseases Clinical Evidence and Evaluation Group 2014
g) Hepatitis C Round Table Discussions from 2016 to date
h) Wales Infected Blood Support Scheme (WIBSS) Project Board 2017-2018
i) The Advisory Committee of the Safety of Blood and Tissues (SABTO) 2019

6) Identify any positions you have held with in relevant committees and working groups and your roles and responsibilities in that capacity

1. I have held the following positions:

a) Trustee of UK Haemophilia Society (2011 to June 2014)
b) Chair of Haemophilia Wales (2014 to date)

7) Describe what you can recall about any matters relevant to the Inquiry's Terms of Reference that were considered by the committee or working group of which you were a member, including your recollection of the information considered by the committee or the working group, the discussions held and the decisions reached.

Ministerial Task and Finish Group Haemophilia Review

Treatment and care of contaminated blood victims in Wales

1. I had been visiting Cardiff Haemophilia Centre since 1989. I am a symptomatic carrier of haemophilia GRO-C. I was aware of the work of the South Wales Haemophilia Group from patients and families attending Cardiff Haemophilia Centre and my contact with the Haemophilia Centre. My grandfather was a haemophiliac who lived until he was 76 and my great uncle, also a haemophiliac, lived until he was 92. I GRO-C have gained an extensive knowledge of the history of their treatment and the treatment of others. Exhibited before me at **Exhibit WITN3988012** is a letter dated 24 June 1985 which is the initial letter I received from Dr Bloom when I was tested as a symptomatic carrier.

2. As a regular visitor to Cardiff Haemophilia Centre, I came into contact with Paul Jenkins, Gareth Lewis, Haydn Lewis, David Edwards, GRO-A and became aware of their work in supporting HIV victims. I also came into contact with many haemophiliacs who at the time did not know they had contracted hepatitis C. Some counselling support was provided by the Social Worker who had been appointed by the Welsh Office for Haemophiliacs with HIV and their families, but it was evident that more counselling and psychological support was needed. Many people had not spoken about their infections due to the stigma associated with HIV and hepatitis C.

3. In 2009 my cousin GRO-A became seriously ill with decompensated liver disease as a result of hepatitis C infection. He was infected through the haemophilia treatment given to him in 1979 which was his first Factor 8 concentrate treatment. My cousin died from hepatocellular carcinoma in 2010 aged 44 years old, a month after Haydn Lewis died and just before Gareth Lewis died. David Morgan, our previous chair of Haemophilia Wales died in 2009.

4. GRO- had no access to Consultant Hepatology opinion and had to pay privately to access clinical advice in London. I brought this to the attention of Professor Peter Collins at Cardiff Haemophilia Centre to find out why GRO- was not given access to a local Consultant Hepatologist. He explained that the Haemophilia Centre were monitoring patients with hepatitis C but as Haematologists, not Hepatologists, they were not specialists in liver disease and did not know when to refer patients to Birmingham, the nearest available site of a Consultant Hepatologist for contaminated blood patients.

5. The previous Hepatologist in Cardiff, Dr Aspinall, left his post in 2007 leaving Dr Andrew Godkin in post who was divided between the University and the Hospital. He was not funded to treat contaminated blood patients and did so on an ad-hoc basis when asked by the

Haemophilia Centre. As a consequence, there was no referral pathway in place for consultant hepatology opinion for contaminated blood patients in Cardiff.

6. When the Task and Finish Group was established in 2011, patients, Haemophilia Clinicians, Gastroenterologists, the Medical Director of WHSCC Geoffrey Carroll and the Deputy Chief Medical Officer (DCMO) Dr Chris Jones, were fully aware of this gap in service provision for over 100 haemophilia and transfusion patients in Cardiff. These patients with progressive liver disease were not being adequately monitored and without constant pressure from Haemophilia Wales nothing would have been done to try to resolve this issue.

7. Exhibited before me at **Exhibit WITN39880013** are The Task and Finish Group Report dated June 2011 and the Task and Finish Group Minutes of meeting dated 1 June 2011.

8. Exhibited before me at **Exhibit WITN3988014** is the Ministerial Announcement made on 1 November 2011 by Lesley Griffiths, Welsh Health Minister, and the responses of Task and Finish Group members to the announcement. The responses omit referencing to the Hepatology Service which was the number one concern of patients. This view was supported by Task and Finish Group clinicians which is exhibited before me at **Exhibit WITN3988015** but was ignored by Welsh Government and WHSCC. If Haemophilia Wales had not maintained pressure on Welsh MPs and AMs progress on this critical service would have been impossible as clinicians, although supportive, had no power to force the recommendations to be implemented.

9. I asked as many patients and families as possible to contact their Assembly Members and MPs and meetings were set up to highlight the issues I had encountered in reviewing Leigh's care. It became apparent that many patients suffering with hepatitis C were not being monitored by specialist Hepatologists and were going through similar distressing deaths. Politicians were unfailingly sympathetic and could not believe what was happening to patients and families as a result of this shortfall in the service.

10. Gaps had been identified in the Hepatology Service but no funding was allocated to resolve this and there was no improvement in the monitoring of patients with hepatitis C. Progress with the recommendations was painfully slow and we were of the opinion that any movement was being blocked by Dr Chris Jones (DCMO) and Geoffrey Carroll (WHSCC). I contacted the Cross Party Group Assembly Members about the lack of progress and consistent blocking. I was also in regular contact with the Task and Finish Group clinicians who were fully supportive of our objectives. Patients and families relayed their concerns to the Assembly

Members and a meeting with Lesley Griffiths took place on 11 March 2013. Exhibited before me at **Exhibit WITN3988016** are my notes of this meeting.

11. Following meetings with Welsh Health Minister Edwina Hart and Dr Chris Jones (DCMO), on 8 March 2011 Edwina Hart announced the establishment of a Ministerial Task and Finish Group to review haemophilia care more generally in Wales. This would be chaired by Dr Chris Jones and would include patient representation, multidisciplinary input from Haemophilia Specialists, Haemophilia Commissioners, Psychologists and a Gastroenterologist. The Group also planned to include local Health Board Officials but they did not engage.

12. I gathered patient experiences from across Wales to highlight the issues affecting the community and presented them to the Group. I consulted with Haemophilia Doctors; Dr Peter Collins, Dr Melinda Hamilton in Bangor, and Dr Ismail in Swansea to ensure we provided an accurate representation of what was needed. The findings of the group were presented to Edwina Hart following which a £96K recurrent funding package for psychological and counselling support was announced.

13. At this meeting we outlined the continuing problems of infected blood patients with advanced liver disease accessing Consultant Hepatology opinion in Cardiff, the lack of monitoring for all infected blood patients with hepatitis C, the lack of progress with the appointment of a Hepatologist with dedicated clinic time for infected blood patients and the continued difficulties accessing hepatitis C treatments. We were not asking for a dedicated post but Dr Chris Jones (DCMO) insisted on answering this as such and continued to state that we were a small group of patients and a dedicated Hepatologist would not be cost effective.

14. We pointed out that the Gastroenterology lead on the Task and Finish Group had recommended a full time Hepatologist at Cardiff and Vale to care for all patients with advanced liver disease, as there was a significant gap in care for all patients, but this was ignored by Welsh Government, WHSCC and Cardiff and Vale Health Board and no one would take responsibility for funding the post. I was very dissatisfied with this response and asked Julie Morgan AM to write to the new Health Minister, Mark Drakeford, who had replaced Lesley Griffiths. His reply of 10 April 2013 is exhibited before me at **Exhibit WITN3988017** in which he agrees to reconvene the Task and Finish Group.

15. It was clear over time that Welsh Government, WHSCC (who were responsible for funding haemophilia care in Wales), and Cardiff and Vale Health Board would not take responsibility for funding the Consultant Hepatologist post and that the pattern of 'assessing the request'-

'consulting with clinicians'- 'consulting with patients'- 'reviewing the data' (which always resulted in a further round of "necessary" consultation) would continue. As a result of the policy of continuous review and no action, good clinical care was not being provided to contaminated blood patients.

16. The policy of 'continuous review and no action' would be further prolonged by a new committee chair and/or a new series of committee members appointed who could justify the requirement to start the process again as they had no prior or current knowledge of the facts or the scope of the previous recommendations. There was also a continuing roster of new faces introduced as 'planning managers' further complicating matters. This process over the course of seven years can be seen as either complete incompetence to manage, or a deliberate attempt to frustrate, the improvement of clinical care in Wales. We assume the same process takes place across the UK resulting in huge inefficiency and waste across the entire NHS estate.

17. The nature of the process can be characterised by an entire lack of budgetary responsibility (nobody seemed to understand who held the budget or what the budget was). Similarly, discussions are now taking place regarding the financial responsibility of the Treasury, Department of Health (DOH), or Devolved Administrations and we have requested that the Inquiry to write to all parties and clarify this matter which is exhibited before me at **Exhibit WITN3988018**. Additionally, there has been no meaningful engagement with Health Boards who have bought a centralised specialised service from WHCSS but not are sure what the service they have purchased is or at what cost.

18. Following representations to the All Wales Advisory Group on Inherited Bleeding Disorders, the Cross Party Group on Haemophilia and Contaminated Blood and individual Assembly Members and MPs and Health Ministers regarding the continued gaps in care, the Task and Finish Group was reconvened on 15 May 2013 for a one off meeting. The minutes of that meeting are exhibited before me at **Exhibit WITN3988019**. There was still no progress with establishing how much was actually spent on haemophilia care in Wales and yet another group was set up, chaired by Stuart Davies (WHSCC) to identify this. This Group continued to try and identify the budget for three years with no outcome.

19. As a result of the one-off meeting, Dr Sunderaaj, a Gastroenterologist, was appointed in 2013 but continued to undergo training in Birmingham. Contrary to the job description and the specific recommendations of the Task and Finish Group, his job description included general Gastroenterology.

20. Exhibited before me at **Exhibit WITN3988020** is a letter dated 15 November 2012 to me from Graham Shortland, Medical Director of Cardiff and Vale Health Board in which Mr Shortland responds to my concerns and states that a Gastroenterologist with a special interest in Hepatology had been appointed and was being trained to support Dr Godkin.

21. It was not until August 2015 that Dr Srivastava was appointed as a Hepatologist with time allocated in his job description at University Hospital Wales (UHW) to see haemophiliacs at joint Haemophilia clinics. Confirmation of his appointment is exhibited before me at **Exhibit WITN3988021**.

22. The All Wales Advisory Group on Inherited Bleeding Disorders was established following the publication of the Task and Finish Group's review of haemophilia care in Wales. The objective of the group was to oversee services for haemophilia and hepatology and provide specialist advice to Health Boards through the Welsh Health Specialised Services Committee on issues regarding inherited bleeding disorders, the monitoring of quality and service provision and to ensure there were plans in place to implement the recommendations of the Task and Finish Group.

23. I registered my concerns with the Chair of the group when I saw the Terms of Reference (exhibited before me at **Exhibit WITN3988022** is the original and at **Exhibit WITN3988023** is the revised Terms of Reference) as it seemed inconceivable that haemophilia services could be discussed and re-commissioned when haemophilia specialists had been excluded from participation. It seemed to me, and other patient representatives, that either the group had been deliberately structured to avoid making progress or that the review and commissioning of health care services without direct reference to haemophilia specialists was a fundamental flaw at the heart of the health care procurement system.

24. Without the engagement of Local Health Boards in Wales, progress was near to impossible. WHSCC kept changing the Chair of the group so there was no continuity. Papers would be circulated at very short notice and minutes would arrive just before the next meeting. The group became so large with so many WHSCC representatives (who had no concept of what was needed and were not briefed) and clinical input was ignored. The psychology funding had been ring fenced by Welsh Government and allocated to WHSCC but we had to keep pressurising them to make progress and appoint the psychologists. Without constant pressure from Haemophilia Wales, patient representatives and the Cross Party Group nothing would have happened.

25. Exhibited before me at **Exhibit WITN3988024** is an email dated 10 August 2015 from Jenny Thorne, Head of Healthcare Associated Infections and Blood Safety Branch, Healthcare Quality Division, DHSS Welsh Government, finally confirming the appointment of Consultant Hepatologist to support the Haemophilia Centre's provision of comprehensive care for patients with acquired hepatitis including those with chronic liver disease. Exhibited before me at **Exhibit WITN3988025** is an email from Dr Chris Jones to me regarding new hepatitis C treatments.

Hepatitis C Treatment

26. Commissioning of Interferon treatments for hepatitis C followed NICE approval in 2004. Many haemophiliacs, despite undergoing as many as four attempts at treatment, failed to clear the virus and remained infected with hepatitis C. They continued to sustain ongoing liver damage and suffer with severe physical and psychological effects of both the disease and the treatment. Initially Interferon treatments in Wales were commissioned by Healthcare Wales but when Healthcare Wales was replaced by the Welsh Health Specialised Services Commission (WHSSC) in 2009, funding for hepatitis C treatments was outside their remit.

27. The Blood Borne Viral Hepatitis Action Plan was produced in 2006 and stated there were 12,000-14,000 with the hepatitis C virus in Wales and only 2.5% were infected via blood or blood products. Only 67 people were treated in 2005. The recommendations were mainly focused on injecting drug users and those who abused alcohol and not on the infected blood cohort who had been infected for 30 years or more and needed ongoing monitoring and treatment. In 2009 we lobbied Welsh Government and the commissioners WHSCC to provide the new Protease Inhibitor treatments Boceprevir and Telaprevir. These treatments had to still be administered with Interferon as Interferon free treatments were not available. Infected blood patients were treated by way of a postcode lottery based on which Heath Board had agreed to fund them or not.

28. Ironically there were patients living outside of Cardiff who were infected in Cardiff but were deemed 'out of area' for hepatitis C funding, their local Health Board refusing to fund treatment. We continued lobbying Welsh Government and the local Health Boards but were told that neither Welsh Government Minsters nor their officials were able to intervene in individual patient's treatment as these decisions were for the relevant Health Board and clinicians.

29. Exhibited before me at **Exhibit WITN3988026** is a reply to GRO-A dated 13 October 2012. GRO-A was a patient with Von Willebrands disease who had contracted hepatitis C

though infected blood products. She was an active member of Haemophilia Wales and campaigned for treatment and support for herself and others. She worked closely with David Morgan, the then Chair of Haemophilia Wales GRO-A health deteriorated due to advanced liver disease and I tried to help her to access the new protease inhibitor hepatitis C treatments.

30. This group of patients were unmonitored and therefore could not prove eligibility for the Skipton Fund Stages 1 and 2 due to the lack of Consultant Hepatology input and monitoring. Many had sustained liver damage from the virus and from multiple previous Interferon hepatitis C treatments. They were severely ill and some died as a result of this. The gaps in service provision for liver disease in Cardiff and Vale are outlined in the 2011 Report 'Improving Liver Health and Outcomes in Liver Disease' in Cardiff and Vale (exhibited below).

31. Exhibited before me at **Exhibit WITN3988027** are the Minutes of a CPG meeting which took place on 23 October 2013. At this meeting, in my capacity at the time of a Trustee of the Haemophilia Society, I made a presentation and put patients' and families' questions to Mark Drakeford (who was the then Health Minister) and members of the Cross Party Group on Haemophilia and Contaminated Blood at the Welsh Assembly.

32. Exhibited before me at **Exhibit WITN3988028** is a letter dated 10 February 2014 from Adam Cairns, Chief Executive of Cardiff and Vale Health Board, to Stephen Harrhy, Interim Director of WHSCC which states '*we are not commissioned or able to support the growing demand for tertiary hepatology*' and that a mapping exercise in 2009 had indicated that a full time Hepatologist was needed.

33. Exhibited before me at **Exhibit WITN3988029** is an email from Stuart Davies, Welsh Health Specialised Services Commission/Chair of All Wales Advisory Group (Inherited Blood Disorders) dated 14 November 2012 regarding 10 patients with decompensating liver disease who had previously failed Interferon treatment but urgently needed access to protease Inhibitor treatments Telaprevir and Boceprevir.

Fibro-scans

34. Four Fibro-scanners were procured in Wales following the Blood Borne Virus Action Plan Wales and Edwina Hart's announcement of same. At the Royal Gwent Hospital in Newport, at Wrexham Maelor Hospital and in Singleton Hospital, Swansea the scanners were used as non-invasive tests to measure the fibrosity of the liver and establish levels of liver damage without the need for biopsies and the increased risk of internal bleeding this brings. At the University Hospital of Wales in Cardiff, the Fibro-scanner had been purchased, but in the

absence of a Consultant Hepatologist it remained in a box in the hospital as there was no one qualified to use it. We were informed by Welsh Government that the Fibro-scanner was available for those with an urgent medical need and as we knew so many people who were in urgent medical and the scanner remained in a box, we continued to raise this issue with AMs and MPs. This resulted in Julie Morgan, AM and Chair of the Cross Party Group, being invited to the Haemophilia Centre in Cardiff to see the Fibro-scanner in its box as yet unopened for the lack of a Hepatologist. We continued to raise the issue of access to availability of Boceprevir and Telaprevir the new protease inhibitor hepatitis C treatments which were also being used with Interferon with Lesley Griffiths, Welsh Health Minister. Exhibited before me at **Exhibit WITN3988030** is a letter dated 14 December 2011 from Lesley Griffiths to Julie Morgan.

Interferon Free Hep C Treatments

35. I attended a Hepatitis C workshop at the Department of Health in December 2013 where Geoff Dusheiko, Hepatologist at the Royal Free Hospital, presented on the success rate of new Interferon treatments. Exhibited before me at **Exhibit WITN3988031** are the notes of the workshop that were released by the Department of Health.

36. I raised the issues of the Infected Blood patients in Wales and particularly those in Cardiff who could not access Consultant Hepatology opinion. Dr Howard Thomas was surprised about this and asked about Dr Godkin but said that there was no clinical time allocated for infected blood patients. I spoke to Geoff Dusheiko following the meeting about the new treatments and he told me there was no input from the Haemophilia cohort to the Advisory Group on Hepatitis and that leading Hepatologists were trying to get an early access programme for those with advanced cirrhosis.

37. The Haemophilia Society decided not to support the introduction of the new Interferon free treatments with little knowledge of them. Exhibited before me at **Exhibit WITN3988032** is an email from Liz Carroll, CEO of The Haemophilia Society, to Bernard Manson, Chair, dated 15 April 2014, disputing claims by Charles Gore, CEO Hepatitis C Trust, that the treatments were clearing the virus.

38. In Wales I identified a small number of such patients who relayed their stories to WHSCC commissioners at All Wales Advisory Group meetings, Cross Party Group meetings and various meetings with Ministers, Assembly Members and MPs. We had to beg for treatment to be funded and eventually WHSCC agreed to an Interim Commissioning Policy of the new Interferon free hepatitis C treatments for the severely ill and new hepatitis C treatments being

rolled out across Wales in 2014. Finally, £13.7 million was ring fenced from Welsh Government for the new Interferon free treatments and everyone who was identified as needing treatment received it regardless of liver disease severity as was the case in England.

Dental Care

39. Many Haemophiliacs in Wales, particularly those with HIV, experienced enormous issues with dentistry due to HIV drugs damaging their teeth. Many local dentists would not treat patients with HIV and many patients in small communities were afraid to register with local dentists. This continues to be a problem for some and should have been resolved sooner. Dentistry issues for infected haemophiliacs resulted in Dental Care pathways being established across Wales which has resulted in some improvements but many infected haemophiliacs would prefer to go the Dental Hospital rather than a local dentist.

Counselling Support

40. From 1987, Mary Dykes was appointed as a Social Worker for haemophiliacs and their families affected by HIV. Mary had counselling experience and had previously worked on the Children's Ward so she knew many of the young haemophiliacs who were infected with HIV. Her post was funded by the Welsh Office and she was employed by Cardiff City Council. Birchgrove Wales applied for 'lottery funding' for two family support workers to be based at Birchgrove Wales offices in 1995. In 1997 two family support workers were appointed and the posts continued until the lottery funding was withdrawn. These were additional posts to the Social Worker posts which were still in existence in 2011. The Social Workers active in the Haemophilia Centre in Cardiff continue to be employed by Cardiff City Council.

41. Following extensive campaigning in Wales to highlight gaps in psychological support in Wales, the Task and Finish Group's Review reinforced this and on-going funding was allocated directly from the Welsh Government for four Haemophilia Psychologists for patients' families and bereaved families. I presented on the background to achieving psychological support in Wales.

42. Exhibited before me at **Exhibit WITN3988033** are the BPS Glasgow Annual Conference Notes.

43. Exhibited before me at **Exhibit WITN3988034** is a BPS Clinical Psychology Forum Article written by myself.

44. Exhibited before me at **Exhibit WITN3988035** is a Mental Health and Wellbeing in Wales Report for the Policy Forum in Wales.

45. As indicated above, without continued pressure from patients, families and Haemophilia Wales, the recommendations of the Task and Finish Group would not be implemented and patients would suffer as a result of this. This was evidenced in 2018. In North Wales, Betsi Cadwaldar Health Board recruited a counsellor, Sali Burns who later left. It seemed that no one knew where the funding was and that it had been absorbed into WHSCC without trace. The lead Psychologist in North Wales, Lisa Heaton Brown, got in touch with Cardiff Haemophilia Centre and myself. I emailed her in order that she could trace what had happened to the psychology funding for North Wales following which the new Psychologist at North Wales Haemophilia Centre, Kate Shakespeare, was appointed. Exhibited before me at **Exhibit WITN3988036** is an email received from Lisa Heaton Brown.

WHSCC Working Group and Project Board Inherited Bleeding Disorders Group

46. The Welsh Health Specialised Services (WHSCC) Working Group and Project Board Inherited Bleeding Disorders Group were set up by WHSCC due to WHSCC's inability to ensure collaboration from Health Boards to deliver the outstanding Task and Finish Group's recommendations. The additional groups contained the same members as previously but with the addition of WHSCC planners and the Haemophilia Society. It was agreed in 2019 that this group should be dissolved and the original All Wales Advisory Group on Inherited Bleeding Disorders would remain in place with WHSCC to engage Local Health Board Representation. This should have been the course of action taken eight years previously following the initial consultation.

Haemophilia Alliance Meetings at the Department of Health

47. The Haemophilia Alliance meetings were initially set up to establish the National Service Specification on Haemophilia.

48. Following the Archer Inquiry in 2009 a committee 'to advise on all provisions necessary to address financial and other needs of haemophilia patients' was established. I was not involved in the group when the Terms of Reference were agreed 'to advise Government on the management of haemophilia in the United Kingdom.' I do not know why financial support was omitted from the Terms of Reference, but I am sure the meetings were not as Archer intended despite Lord Morris and Baroness Campbell of Surbiton's representations in the House of Lords. These are exhibited before me at **Exhibit WITN3988037.** The background

to the establishment of these meetings which references Baroness Darzi's and Lord Morris's statement (Hansard 28 April 2009) is exhibited before me at **Exhibit WITN3988038**. Lord Darzi does not mention the Haemophilia Alliance meetings (as stated in the UKHD-HA paper) – only the SABTO meetings.

49. The first Haemophilia Alliance meeting took place on 20 November 2009. The minutes have been exhibited before me at **Exhibit WITN3988038**. However, the first meeting I attended was on 14 November 2011 as a patient representative at which I met Mrs Della Hirsch - a parent of a haemophiliac infected with hepatitis C. The meetings were jointly chaired by the Head of Blood Policy at the Department of Health, Rowena Jeacock, and in her absence Dr Ben Cole. In attendance were Jonathan Wilde of the United Kingdom Doctors' Haemophilia Organisation (UKHCDO) and Liz Rizzutto, Chair of The Haemophilia Society. The minutes were often very sketchy and inaccurate, and comments and amendments were not included in the final minutes. For example, I gave a talk on the gaps in care in Wales at the first meeting I attended and it is noted that I commented there was no 'Haematologist' at Cardiff CCC which is not correct as I said there was no Hepatologist at Cardiff. I also spoke about counselling and the vCJD points relating to access to endoscopies and decontamination of instruments and testing but this is not reflected in the minutes. These minutes are exhibited before me at **Exhibit WITN3988039**.

50. The hepatology issue was very much seen as a Welsh problem. I handed a letter to the haemophilia doctors at the meeting which is dated 16 July 2009, and is exhibited before me at **Exhibit WITN3988040,** regarding a Welsh patient who had been refused an endoscopy in Birmingham due to his vCJD 'at risk' status. I asked why there had not been further communication from the Department of Health following their letter to at risk patients in 2004. I asked for a UK wide approach to be adopted moving forward to ensure that patients were well informed. It was obvious that neither the Department of Health nor the UKHCDO would take responsibility for this. The CJD Incidents Panel was abolished in 2012 and incidents became the responsibility of individual hospitals.

51. I raised issues in Wales relating to the ambulance service whereby Welsh patients with HIV and hepatitis C were in emergency situations and particularly when patients were at risk of death via decompensated liver disease they were being taken by ambulance to their nearest hospital and not to their nearest Haemophilia Centre. I knew this was happening in other parts of the UK and asked for a UK wide approach to be taken by the Department of Health and UKHCDO. In Wales this was taken forward and haemophilia patients were issued with letters to ensure they were taken to Haemophilia Centres and not local hospitals. Exhibited before

me at **Exhibit WITN3988041** is the Ambulance Services letter for Welsh haemophilia patients.

52. I also raised issues about the accurate recording of deaths due to contaminated blood. Why did the Department of Health only ask for the fact of death to be recorded on Death Certificates and not the cause of death? Dr Ben Cole of the Blood Policy Unit said it was up to the doctor who was certifying the death to decide the cause of death recorded on the death certificate. As a result of this lack of direction a patient dying from liver failure/hepatocellular carcinoma may not have hepatitis C recorded as cause of death, similarly HIV patients may be recorded as having died from pneumonia.

53. The Department of Health did not circulate minutes efficiently to everyone on the circulation list. Minutes were sent just prior to the next meeting and adjustments and comments were not included. The whole day of the meetings would be taken up with various presentations from Department of Health officials and some or other Haemophilia Society initiative but the real issues affecting the haemophilia infected blood community were tagged onto the end. Time was not allocated for them and any issues relating to financial support were outside the remit of the meeting. Welsh Government was disinterested in the meetings and did not play an active part. I complained to the Welsh Health Minister, Lesley Griffiths, about this, as had Welsh Government taken an active role, then I think more progress could have been made. In the November 2013 Haemophilia Alliance meeting Welsh Government 'had nothing to report', but we had already been told by Mark Drakeford that funding was in place for Consultant Hepatologist.

54. I felt that all real issues were blocked by Rowena Jeacock and Ben Cole. There was little interest from UKHCDO in the meetings; Charles Hay replied to one patient's concerns saying it was, quote- 'Bullshit'. I witnessed very poorly patients now deceased attending the meetings to try to resolve issues of monitoring and support with no action ever having been taken. Eventually the decision was taken that the group served no purpose and should be replaced by the Clinical Reference Groups (CRG) in England. I did not agree with this decision as these meetings were intended by Lord Archer to be an appropriate forum to discuss matters of care and support across the whole of the UK.

55. The Haemophilia Alliance had already omitted financial support from the Terms of Reference. The CRGs were designed to address issues in England only and there would be no direct contact with the Department of Health if the Haemophilia Alliance meetings were dissolved. I was outvoted and no one at the meeting supported me. I tried to raise additional concerns and Dr Ben Cole, who was chairing the meeting instead of Rowena Jeacock, packed his bag

and walked out of the meeting before it was concluded. There is currently no UK wide group as Lord Archer had intended. Wales have the All Wales Advisory Group on Inherited Bleeding Disorders, Scotland has a similar group, England and Northern Ireland currently have no body in place.

56. Exhibited before me at **Exhibit WITN3988042** is the November 2013 - January 2014 Influencing Update from Bernard Manson, Chair of the Haemophilia Society.

57. Exhibited before me at **Exhibit WITN3988043** are communications dated 27 March 2014 between Haemophilia Society and myself regarding **GRO-A** and Macfarlane Trust issues.

58. In 2013 the Department of Health sold the Government's 80% stake in Plasma Resources UK to Bain Capital, for £230 million. Initially, the APPG was told that Treasury rules prevented this from happening because money from sell-offs is categorised in capital spending rather than revenue spending. However, the Department of Health regularly transfers money from its capital budget over to its revenue budget: it would merely have to make a similar transfer in order to make use of the funds from Plasma Resources UK. Diana Johnson MP wrote to the new Under-Secretary of State for Public Health, Lord Prior of Brampton, reiterating her calls for the funds from the sale of Plasma Resources UK to be used in this way.

59. Exhibited before me at **Exhibit WITN3988044** is a letter from Lord David Owen to the Prime Minister dated 15 March 2013 which Lord Owen forwarded to me. I raised this at the Haemophilia Alliance meetings on 3 June 2013 with Rowena Jeacock but the reply was all budget related, noting that the plan needed upgrading and 'the British Government were not in a position to invest'. I contacted Owen Smith MP for Pontypridd on 12 June 2013. Exhibited before me at **Exhibit WITN3988045** are emails from Owen Smith and Dan Poulter, Junior Health Minister, and at **Exhibit WITN3988046** is a letter from Dan Poulter to Owen Smith dated 16 July 2013.

Rare Disease Group

60. I was part of a team who developed the UK Strategy for Rare Diseases alongside the Genomics and Rare Disease Team at the Department of Health to ensure early diagnosis, coordination of care and to empower patients with rare diseases.

61. On 25 July 2013 I attended a Rare Disease Workshop at the Department of Health and Earl Howe, Parliamentary Under Secretary of State for Quality and Control at the Department of Health, spoke about the importance of the patient being at the centre of the development of

services and their absence was often the reason for failure. Geoffrey Carroll, Medical Director of Welsh Health Specialised Services Commission, spoke at the workshop.

62. I was a member of the Rare Diseases Clinical Evidence and Evaluation Group chaired by Geoffrey Carroll to improve services for Rare Diseases in Wales and to ensure access to Centres of Excellence for patients with Rare Diseases. The Welsh Implementation Plan for Rare Diseases was launched by Mark Drakeford, Welsh Health Minister, and Dr Chris Jones, Deputy Chief Medical Officer, on 28 February 2014. The group met on 17 February 2014, 27 June 2014 and 10 September 2014 to discuss the Welsh Implementation for Rare Diseases plan to ensure that rare diseases are viewed as priority by Welsh Government. I attended a patient engagement event to review the appraisal of Orphan and Ultra Orphan medicines in Wales.

63. I have also worked with Emma Hughes, Wales Development Officer, at the Genetic Alliance and attended various workshops and Rare Disease Reception meetings and networking events with non-haemophilia patients who were having difficulties accessing specialised services in Wales. Some Rare Disease patients were the only ones with a particular condition living in Wales. I advised Emma Hughes on setting up the Cross Party Group on Rare Diseases at the Welsh Assembly to ensure a co-ordinated approach in Wales.

Hepatitis C Elimination Roundtable Welsh Assembly

64. In 2006 Public Health Wales launched the Blood Borne Viral Hepatitis Action Plan for Wales to assess provision of specialist treatment and support for 12,000-14,000 hepatitis C patients living in Wales, which identified considerable unmet need and no provision of a budget. In 2010 The Blood Borne Virus Action Plan was launched in Wales, but the focus remained on the non-infected blood cohort who only accounted for 2.5% of the total cohort of infected patients.

65. At this stage there was still no funded Consultant Hepatologist in Cardiff and Vale where the majority of infected haemophiliacs in Wales had been infected. The WAGE Delivery Plan 2009-2010 is exhibited before me at **Exhibit WITN3988047**. Myself and the Haemophilia Wales Trustees have been involved in many roundtable meetings at the Welsh Assembly and our Trustees have provided on going peer support to many non-blood infected hepatitis C patients and families in Wales (Hepatitis C Trust, Gilead and Abbvie).

Wales Infected Blood Support Scheme

66. Many of the infected and affected victims had experienced difficulties accessing financial support from the Macfarlane Trust, Skipton Fund and Caxton Foundation. Their additional stress and suffering were a direct result of the way they had been treated by various scheme administrators. In Wales we had a clear vision of the threshold to be achieved to provide an acceptable service for beneficiaries. The Wales Infected Blood Support Scheme was established on 1 November 2017 following continued lobbying of both Westminster and Welsh Government and patient engagement and experiences (organised and collated by Haemophilia Wales and the Cross Party Group). This highlighted the need for a tailored, holistic approach with psychological support and welfare and benefits advice for both the infected and affected.

67. I played a major role in informing Velindre Trust, NHS Wales Shared Services Partnership (NWSSP) and Welsh Government about what was needed in Wales as I had first-hand experience of how people were being treated by the existing schemes in England. When the Project Board's work was completed, Nigel Miller, a Trustee of Haemophilia Wales, and I were invited to sit on the Wales Infected Blood Support Scheme (WIBSS) Management Group which met on 3 May 2018 and 23 November 2018.

68. Nigel Miller and I felt as Trustees of Haemophilia Wales it was not appropriate for us to sit on the WIBSS Management Group because as a charity we would potentially be advising beneficiaries. Additionally, Debbie Jones, who was a member of Contaminated Blood Campaign organised by Glenn Wilkinson, was posting accusations on social media that Haemophilia Wales was being funded by WIBSS/Welsh Government and were consequently ignoring Stage 1 hepatitis C beneficiaries. This group lodged a petition at the Welsh Assembly by two of the campaigning groups in England as the Welsh Government had not introduced the Special Category Mechanism like in England. We did not want them to introduce this as some of our Haemophilia Wales members and one of our Trustees were under the English scheme but were having difficulty proving eligibility for this. Haemophilia Wales issued a statement in response which is exhibited before me at **Exhibit WITN3988048**.

69. Exhibited before me at **Exhibit WITN3988049** is an email from myself to Wales Infected Blood Support Scheme dated 13 August 2018.

70. Freedom of Information Requests were also sent to WIBSS and the Welsh Government about my dealings with them so Nigel Miller and I asked to be removed from the Management Group and suggested that WIBSS set up a Stakeholder Group and to invite interested beneficiaries to this group. As a result of ongoing work with WIBSS and the Welsh Government about a panel to decide eligibility for enhanced payments, a more acceptable approach was taken by

WIBSS beneficiaries to apply for increased Stage 1 payments by self-assessing psychological impact with questions, without the need for medical supporting evidence. This is still working well today.

The Advisory Committee of the Safety of Blood, Tissues and Organs (SABTO)

71. When the Haemophilia Alliance meetings were dissolved the Department of Health decided that they were not the most appropriate forum for patient representatives. In my opinion, the concept of a statutory committee had been blocked by Earl Howe, Lord Darzi and others despite Lord Morris and Baroness Jane Campbell of Surbiton's continued pressure following the Archer Inquiry. The Government's view was reinforced by Edwina Hart's Welsh Health Minister's statement; 'Response to Independent Inquiry into Contaminated Blood and Blood Products'. Exhibited before me at Exhibit **WITN3988050** is a statement of Edwina Hart dated 20th May 2009.

72. On 11 March 2019 I attended one stakeholder engagement meeting with the Advisory Committee of the Safety of Blood, Tissues and Organs (SABTO) at the Department of Health regarding SABTO's proposed recommendations of the Paediatric Components Working Group. Haemophilia Wales could not support the Paediatric Components Working Group recommendations that the risk reduction measures for individuals born after 1 January 1996 or with thrombotic thrombocytopenic purpura (TTP) be withdrawn. Experts in vCJD were at the meeting and I highlighted the issue of haemophiliacs receiving vCJD 'at risk' letters in 2004 from the Department of Health on the same day as the story hit the press. I also raised that haemophiliacs have been labelled as 'at risk' on medical notes and have difficulties accessing investigations as a result.

Section 4 Research and investigations

8) Describe and provide details of any investigations or research you have undertaken that is relevant to the Inquiry's Terms of Reference

1. Exhibited before me at **Exhibit WITN3988051** is an article from Blood Journal dated 1st August 2007 Vol 110 No 3 page 815-825 titled, 'Mortality rates, Life Expectancy and causes of death in people with Haemophilia A and B in the UK not infected with HIV' (Vol 110 No 3 page 815-825).

2. In 2010 I contacted Lord David Owen regarding the contaminated blood scandal and asked him to help get justice for victims. He replied stating that he had made many representations

in Parliament and to the Ombudsman but had been unsuccessful in getting the issues addressed. He attached his submission to the Archer Inquiry regarding self-sufficiency and the destruction of his departmental papers which is exhibited before me at **Exhibit WITN3988052**.

3. Meetings arranged by Baroness Lynne Featherstone with Lord Prior and Chris Wormwald, Permanent Secretary Department of Health, resulted in the withdrawal from use of the Department of Health's 'Self Sufficiency in Blood and Blood Products 2006' being used as the defacto document to brief Government Ministers. My notes of these meetings are exhibited before me at **Exhibit WITN3988053**.

Hepatitis C Diagnosis and Treatment

4. In Wales there were 12,000 -14,000 people with hepatitis C and only 2.5% of those contracted the disease via blood products. In the general population liver disease accounts for 1 in 10 patients in critical care at University Hospital of Wales and liver disease generally is a growing problem. Despite this, the University Hospital of Wales was seriously understaffed in terms of liver specialists compared to Hospitals in England. The then Chief Executive of NHS Wales, David Sissling, made one of his main objectives in his Annual Report 2013 to 'reduce emergency admissions'. How could that be achieved when patients with advanced liver disease were not being monitored, there was no single pathway of care, no dedicated Hepatologist and they were being admitted through A&E or through the Haemophilia Centre with all the issues of waiting on a trolley without a bed?

5. Many with hepatitis C and decompensated liver disease had reported being swollen with ascites but having to be on a trolley for hours and hours. Cardiff and Vale University Health Board had produced a report called 'Improving Liver Health and Liver Outcomes' in 2011 which identified a future service model but it remained unimplemented. Exhibited before me at **Exhibit WITN3988054** is a copy of that report. The representative from the National Specialist Advisory Group on Gastroenterology who was part of a Haemophilia Review stated that; 'Without the appointment of a consultant Hepatologist at Cardiff the care of this group of patients would not improve.'

6. In December 2013 Bernard Manson, Chair of the Haemophilia Society, asked one of the Haemophilia Wales Trustees to telephone into a Department of Health Workshop on new hepatitis C treatment and Skipton Fund data. I attended the meeting and asked Bernard to ask the Department of Health for Joseph Peaty, a co-infected haemophiliac with a background in statistics, to attend, but this was refused by Dr Ben Cole of the Department of Health.

Professor Geoff Dusheiko, Hepatologist from the Royal Free Hospital, presented on the new Interferon free hepatitis C drugs with a 96% clearance rate. I raised the issues of lack of Consultant Hepatology input in Wales with Professor Howard Thomas. My email correspondence relating to this workshop is exhibited before me at **Exhibit WITN3988054**.

7. Professor Dusheiko told me after the meeting that leading Hepatologists had been lobbying for early access but no progress was being made. By April 2014, NHS England was still refusing to fund the new Interferon free drug. Professor Thursz, Consultant Hepatologist at St Mary's in London, was seeing one of our Welsh patients as we did not have access to Consultant Hepatology opinion in Cardiff. He needed a liver transplant but had previously failed Interferon treatment three times. Professor Thursz told us about his concerns regarding Malcolm Qualie, Lead Pharmacist NHS England, who was saying that they had to follow a process to fund the treatment. Professor Thursz said that in reality they were 'inventing the process and creating new hurdles along the way'. Exhibited before me at **Exhibit WITN3988056** is an email from Professor Thursz to the patient dated 7 April 2014.

8. Professor Thursz told us that there had been no representation from the haemophilia community and suggested we attend a press conference at the Kings Fund, Cavendish Square, to lobby for funding for contaminated blood patients - which we did. There we heard from leading Hepatologist, Mathew Cramp, that funding was continuing to be refused and patients were dying because of this. I had been trying to get early access to Interferon free treatment since December 2013 but Liz Carroll, CEO, and Bernard Manson would not support the call for early access to treatment. I decided it was easier to lobby Welsh Government and the Welsh Commissioners ourselves. There were about ten infected blood patients who had decompensated liver disease or were near to decompensating and it was important that they were treated so they could go on the transplant list. We continued to lobby Welsh Government and on 2 July 2014 an Interim commissioning Policy for Sofosbuvir was announced for the severely ill. This policy is exhibited before me at **Exhibit WITN3988057**.

9. There were further problems regarding NICE approval in England and I contacted my MP at the time, Jonathan Evans, who met with Andrew Dillon the Chief Executive of NICE. Exhibited before me at **Exhibit WITN3988058** is an email from Jonathan Evans to myself, which in my opinion supports the view of the leading UK Hepatologists at the time that approval for the new Hepatitis C interferon free treatments were delayed by NICE with pressure from NHS England who did not want to fund the drugs due to cost alone.

10. By 2016 the severely ill in Wales had been treated and had cleared the virus but those without cirrhosis had not been treated and so there were still problems accessing hepatitis C

treatment in Wales. In England they were only planning to treat 10,000 per year. I contacted Baroness Featherstone to raise this issue in the House of Lords and on 28 April 2016 she asked of Lord Prior that none of the £125 million funding announced for Infected Blood support in England be used to fund hepatitis C treatment. This approach had been planned by the Government. A copy of the Question in the House of Lords to Lord Prior (and the responses), together with email correspondence between myself and Baroness Featherstone is exhibited before me at **Exhibit WITN3988059.**

11. A debate ensued and he agreed to meet her to discuss further. The meeting with Lord Prior took place on 13 June 2016. This was following indications in Parliament that the fund should be used to pay for Interferon free hepatitis C treatments in England. In Wales everyone had been treated regardless of severity of disease but this was not the case in England. Rowena Jeacock, Head of Blood Policy at the Department of Health, was at the meeting and used the same blocking tactics as at previous Haemophilia Alliance meetings. Exhibited before me at **Exhibit WITN3988060** are my notes for the meeting and at **WITN3988061** are my notes of the meeting.

12. I presented on the unfairness of enhanced access to hepatitis C treatment being funded by Skipton, patchy access to Hepatology opinion, incomplete data, mental health issues, access to life assurance and mortgage protection, the need for a statutory inquiry into the scandal, pre-devolution issues and ongoing support for widows and dependants. Following the meeting there was no feedback, notes or minutes but Baroness Lynne Featherstone (who was a former MP for Hornsey and Woodgreen and also Della Hirsch's sister and an aunt of a haemophiliac) contacted Lord Prior privately to voice my concerns about Rowena Jeacock.

13. Exhibited before me at **Exhibit WITN3988062** are my notes of my meeting with Baroness Featherstone on 1 November 2016 where we strategized the pathway to a public inquiry.

14. Exhibited before me at **Exhibit WITN3988063** are the notes of the APPG meeting with Diana Johnson, Lord Prior, Alistair Burt and the Haemophilia Society that took place on 15 November 2016 regarding improved financial support, sale of Plasma Resources UK (PRUK) and the pressing need for a public inquiry.

15. I refer again to **Exhibit WITN3988053** above which is the minutes of a meeting with Chris Wormwald, Permanent Secretary, Department of Health, that took place on 20 June 2017. This meeting was arranged by Baroness Featherstone following the Lord Prior meeting. It was confirmed that Rowena Jeacock and Ben Cole no longer worked for the Department of Health. Chris Wormwald's father was on the circulation list of Diana Walford's memo and he

confirmed that his father had worked in the Department of Health in the 1970s and 80s. The notes of the meeting highlight the issues around progress being blocked by Rowena Jeacock and 'Self-sufficiency in Blood and Blood Products' being the defacto document used to misinform Department of Health officials and Ministers.

16. Baroness Featherstone arranged a meeting with Professor JP Allain in the House of Lords as Professor Ted Tuddenham had indicated he may be worth meeting when we spoke after the Bad Blood Film Premiere on 29 September 2016 organised by Jason Evans. Exhibited before me at **Exhibit WITN3988064** are the minutes of the meeting that took place on 31 October 2016 at the House of Lords. Exhibited before me at **Exhibit WITN398865** are Baroness Featherstone's notes of the film.

Transfer of reserves from Macfarlane Trust to Terence Higgins Trust: What happened to Honeycombe and Wilson Legacies?

17. In 2018 I attempted to carry out investigation into what had happened to the money in the Honeycombe and Wilson Legacies following the establishment of the Macfarlane Trust and subsequently the Terence Higgins Trust. Exhibited before me at **Exhibit WITN3988066** and dated 4 May 2018 is an email response from Catherine Cody, Welsh Government, advising of the reply she received from Department of Health in regard to who has accountability for the money in the schemes.

9) Outline the information or material that you found through your investigative efforts or research

1. I made contact with Lord Patrick Jenkin (father of Bernard Jenkin MP) in April 2013 and we met at Lord Morris' House of Lords Reception and spoke about his papers being destroyed. I asked him to the next APPG meeting which he attended and sent the emails that are exhibited before me at **Exhibit WITN3988067**.

2. In respect of funding for hepatitis C treatment - prior to direct funding being ring fenced by Welsh Government for hepatitis C drugs, patients infected with hepatitis C through the NHS were not eligible for treatment unless they lived in a Health Board where funding had been approved. There were instances when Cardiff and Vale Health Board would approve funding but other Health Boards would not and we would have to help patients get funding. Had monitoring from Consultant Hepatologists and funding been available for this group of patients nationally there is no doubt lives would have been saved. The WHSCC would not fund them,

some Local Health Boards would not fund them and Haemophilia Centres could not fund unless they lived in a specific catchment area.

3. I visited many Assembly Members and MPs to help patients get funding. Due to the delays in the appointment of a Consultant Hepatologist in Cardiff and patients only being seen by Dr Godkin, but no funding provision for this, some patients paid for a private Consultant Hepatologist opinion in England. Many patients died as they were not monitored by specialists.

4. I learned about the new Interferon free HCV drugs at an HCV Workshop I attended at the Department of Health chaired by Dr Ben Cole in December 2013. I spoke to the group, including Dr Howard Thomas, about the lack of Consultant Hepatology opinion in Cardiff. Professor Geoff Dusheiko, Hepatologist at the Royal Free, presented on the new Interferon free treatments with near to 100% cure rate for Genotype 1. Professor Dushieko told me there had been no input from the haemophilia cohort which I found shocking. Exhibited before me at **Exhibit WITN3988068** is my note of the workshop. The minutes have been exhibited earlier in this statement at **Exhibit WITN3988031**.

10) Describe the efforts that were involved in obtaining the information or material referred to in Question 8

1. I have addressed this in my response to Question 8.

11) State whether there is information or material that you were unable to obtain access to during your investigative research work and if so provide an outline of what you were seeking but were unable to obtain

1. Despite my extensive research, campaigning and lobbying, I have not been able to find satisfactory answers to the following questions:
   a) When it was known that haemophilia patients had received contaminated products then why was the decision not taken by the UKHCDO to clear the shelves of all the old stock?
   b) Why isn't access to Consultant Hepatology opinion and hepatitis C Treatment and monitoring included in the UKHCDO National Service Specification?
   c) When Haemophilia doctors knew that everyone who had received Factor concentrates prior to 1991 was hepatitis C positive, why didn't they ensure that funding was allocated from Central Government for hepatology and psychological support?
   d) Why DCMO Dr Chris Jones appeared to be unaware of infected blood/liver disease?

e) Why were the Welsh Commissioners Welsh Health Specialised Services Committee (previously Healthcare Wales and originally responsible for funding hepatitis C drugs) able to relinquish responsibility for solely funding hepatitis C drugs?

f) How was the Consultant Hepatologist at University Hospital of Wales eventually funded?

g) Why are liver disease delivery plans and blood borne virus plans entirely focused on injecting drug users, alcohol users and obesity with no mention of infection via NHS blood and blood products?

h) What are the details of the sale of Plasma Resources UK from the Department of Health?

i) What is the up to date state of knowledge in respect of vCJD and the cleaning of instruments and testing?

j) If the risk is now known to be lower than originally thought, then why haven't patients been informed and their 'at risk' status amended?

k) How are the devolved schemes funded? In the letter exhibited previously at **Exhibit WITN3988009** from Vaughan Gething he states; 'I am pleased to advise that the Department of Health has now confirmed it will continue to fund payments for the current Spending Review Period 2020-2021'. If the money is coming from the Department of Health then why didn't victims in Wales receive an increase in payments in April 2019 alongside English victims?

l) We are told by Welsh Government that every announcement on financial support in England is always made without prior warning to Welsh Government. Is this true and if so why does it always happen?

m) Why is route of infection not considered when deciding criteria for treatment? NHS contaminated blood victims were themselves being discriminated against as they did not engage in high risk activities related to infection and they would adhere to treatment regimes and would not re-infect.

n) Haemophiliacs were a known group of infected patients so why weren't they traced and treated? Why hasn't everyone who received an infected blood transfusion been traced?

o) Why are GPs so ill informed about hepatitis C?

p) Why trainee doctors and nurses aren't educated about infected blood and why is there not a care pathway in place for contaminated blood patients?

q) Why don't doctors routinely ask patients if they have had a blood transfusion?

r) A key question is why the UKHCDO National Service Specification on Haemophilia did not include access to HCV treatments to resolve issues of postcode lottery for haemophilia patients infected with hepatitis C via Haemophilia Centres?

s) Why did it not include on-going monitoring for HCV and access to Consultant Hepatology opinion? (This has now been included in the Welsh specification but not in the English).

t) Why is hepatitis C treatment not in Welsh Health Specialised Services Welsh Commissioners for Haemophilia Care? WHSCC was re-formed in 2010 and replaced Healthcare Wales headed by Geoffrey Carroll. They dumped hepatitis C responsibility which is why it was so difficult to get the infected blood patients treated.

u) Why did the Macfarlane Trust transfer reserves to the Terence Higgins Trust and why was information on beneficiaries transferred to Russell Cooke solicitors?

Data

2. It has been extremely difficult to secure accurate data on deaths associated with HIV and hepatitis C as the Department of Health has not collected data accurately. Only the fact of death and not the cause of death have been recorded.

3. After 35 years there is still no accurate and commonly held data recording the number of deaths and the number of infected and affected families, most of the data is estimated. The collection of data continues to cause frustration and division amongst the affected groups and importantly the lack of agreed data makes it incredibly difficult to assess the true scale of the problem.

4. In dealing with bereaved families and the families of those attempting to access the support system, the lack of a clear record of the infection route, coupled with misleading, doctored or missing medical records leads to extreme distress amongst the affected who feel they are reduced to begging in the absence of clear data and accurate medical records.

Section 5 Individual campaigning activities

12) Outline the aims and outcomes of any campaigning activities insofar as relevant to the Inquiry's Terms of Reference that you have undertaken as an individual

1. I campaigned to ensure there was no cut-off date for posthumous claims for Skipton Fund payments in Wales as many bereaved families could not provide proof of the source of their infection on medical records and were not eligible for support. Exhibited before me at **Exhibit WITN3988069** is the response of Edwina Hart, Welsh Health Minister dated 8 March 2011 to the Contaminated Blood Review.

2. I also campaigned for Fibroscanners to be used as a non-invasive test instead of biopsies in Wales to prove eligibility for Skipton criteria. This resulted in the Task and Finish Group being

established to identify gaps in haemophilia care in Wales and with counselling support to be reviewed.

3. Exhibited before me at **Exhibit WITN3988070** is a letter dated 29 March 2011 to Assembly Members from Edwina Hart, Welsh Health Minister, regarding discretionary support, the establishment of the Caxton Foundation, posthumous claims and absence of life assurance and mortgage protection for infected blood patients and families. I believe the review in England did consider insurance for infected individuals. However, I felt the scheme operating in the Republic of Ireland provided a far more appropriate level of support and requested comment as to why the review rejected such a scheme for the UK.

4. The Secretary of Health replied that the Department of Health review looked at the Irish Insurance scheme and that the take up was extremely low, which rendered that model as being unlikely to represent value for money. I would argue that this is not true and could be clarified by Brian O'Mahony, CEO of the Irish Haemophilia Society, as Haemophilia Wales visited the Irish Haemophilia Society in Dublin with Haemophilia Scotland on 15 July 2015. Exhibited before me at **Exhibit WITN3988071** are answers from Brian O'Mahony arising from a meeting with the Irish Haemophilia Society in Ireland in 2015. The meeting was a fact-finding mission about the Lindsay Tribunal and the Irish scheme. Haemophilia Wales (myself, Tony Summers and David Thomas) and Haemophilia Scotland (Bill Wright, (Chair) and Dan Farthing (CEO)) attended too.

5. I campaigned extensively for a Judge led public inquiry – details set out above.

6. I raised issues of care and support in Wales and this resulted in a review of haemophilia care in Wales and the establishment of the Task and Finish Group on Haemophilia being set up by the Welsh Government.

7. I campaigned for a committee to advise on haemophilia and the All Wales Advisory Group on Inherited Bleeding Disorders was established in 2011.

8. I campaigned for hepatology access to ongoing monitoring and access to Consultant Hepatology opinion for those infected with hepatitis C – details set out above.

9. I campaigned for access to hepatitis C drugs via Local Health Boards prior to funding being ring-fenced. Previously exhibited before me at **Exhibit WITN3988056** dated 7 July 2014 is email correspondence from Professor Mark Thursz regarding early access to Sofosbuvir. The Exhibit starts with an email from Professor Thursz to a Haemophilia Wales Trustee explaining the problems of early access with NHS England and NICE approval. In Wales, after much

pressure, we were able to secure early access but the Haemophilia Society did not lobby for this in England.

10. I campaigned for counselling and psychological support for affected victims in Wales which resulted in the appointment of Psychologists at Cardiff, Bangor and Swansea for haemophilia patients, families and bereaved families affected by contaminated blood. A Consultant Psychologist and one lead counsellor were also appointed for Wales Infected Blood Support Scheme.

11. I campaigned for Improved social work provision at Cardiff Haemophilia Centre.

12. I campaigned for inclusion of widows and widowers in the Welsh Infected Blood Support Scheme to provide on-going non means tested payments. This only resulted in a three year payment for the newly bereaved and three year equivalent for the historically widowed in addition to the £10k one off payment under the English scheme. However, we continue to campaign for life-time security for widows and widowers.

13. I campaigned for the appointment of the Welfare and Benefits advisors to the Wales Infected Blood Support Scheme.

14. I campaigned for psychological self-assessment for Stage 1 victims with hepatitis C in Wales.

13) Describe the various campaigning activities you have undertaken including meetings, demonstrations, complaints and letter writing in relation to clinicians, NHS bodies, blood transfusion services, pharmaceutical companies, financial assistance schemes, government ministers, MPs, MSPs, Assembly Members or MLAs and or government departments and civil servants.

1. I have set out above the details of the meetings I have attended and the lobbying and campaigning activities I have been involved in. The other side of my role in Haemophilia Wales has been producing newsletters and updates and providing personal support and assistance to the victims we support.

2. I have frequently contacted Pfzier, Roche and Sobi Pharmaceutical companies asking for contributions towards Haemophilia Wales annual events.

3. I have written many letters to Trusts on behalf of Haemophilia Wales members who were having difficulties accessing financial support.

4. I have written to and lobbied Assembly Members, MPs and peers including Lord Morris (2010-2011), Lord Patrick Jenkin (2011), Lord Warner (2006), Baroness Llora Finlay of Llandaff, Baron Dafydd Wigley, Baroness Jenny Randerson (and in her previous role as an Assembly Member), and Baroness Gale of Blaenrhondda.

5. Over the years, I fought against resistance from successive Governments to provide justice and support to contaminated blood victims and families. Following the Archer Inquiry, the 2009 Government refused to implement the Archer Inquiry recommendations.

6. In 2011 the review of Contaminated Blood Support by Ann Milton, Junior Health Secretary, made some minor changes to the system but did not address the main issues. I contacted infected and affected families and asked them about their experiences and concerns. I compiled patient experiences from all over Wales. I asked patients and families to contact their MPs and Assembly Members and I offered help and support to them and attended meetings with them if they needed help highlighting the issues. I also made contact with the above peers.

7. On 2 June 2010 I arranged a coach to London and brought a large group from Wales to join the protest and march from Trafalgar Square to No 10 when Lord Morris, President of the Haemophilia Society, and campaigners, presented a petition to No 10. We then went to meet with the Welsh MPs in Parliament. Owen Smith, who was the newly elected MP for Pontypridd, had been contacted by a number of constituents about contaminated blood and he instigated the first Back Bench Business Debate to be held on 14 October 2010 (by the time the date was set for the debate, Owen had been promoted to a Minister and so Geoffrey Robinson led the debate in his place).

8. In 2011 the Contaminated Blood Bill was tabled. Earl Howe stated that nothing in the Bill would improve treatment or services for those affected and we should not be passing legislation simply because we feel compassion for those affected. Regarding Lord Morris' proposal in the Bill for Health Amendment cards as in Ireland for priority access to services for the infected, Earl Howe said '*Priority card holder scheme would give priority access to everyday treatments like chiropody.... And jumping the organ donation queue when those decisions are based on clinical need and nothing else.*'

9. **Timeline of activities leading to the public inquiry:**

2009 onwards

Contacting AMs, MPs and Peers, Protests in Westminster alongside Lord Alf Morris and other campaigners;

14 December 2011

Lesley Griffiths, Welsh Health Minster, replies to Julie Morgan re availability of Fibroscanners and hepatitis C treatments;

11 March 2013

Meeting with Lesley Griffiths, Welsh Health Minister, raised monitoring of hepatitis C patients and access to Consultant Hepatology opinion, inadequacies of the Trusts and exclusion of widows in the schemes;

2 April 2013

I wrote to Julie Morgan asking for Task and Finish Group to be reconvened due to lack of progress of WHSCC and local health Boards;

10 April 2013

Mark Drakeford replies to Julie Morgan and a meeting is agreed;

17 April 2013

APPG meeting with Anna Soubry Junior Health Minister (the Minutes are exhibited before me at **Exhibit WITN3988072**);

23 October 2013

Meeting with Mark Drakeford Welsh Health Minister: Consultant Hepatology, life assurance, mortgage protection, counselling support, the need for a public Inquiry;

15 January 2015

Contaminated Blood Debate;

15 July 2015

Haemophilia Wales visited Irish Haemophilia Society: Brian O'Mahony and Declan Noon present on how they achieved Lindsay Tribunal and compensation;

April 2016

Briefing for Welsh MPs in Parliament organised by Haemophilia Wales and Jessica Morden, MP Newport East;

12 April 2016

Backbench Business Debate and Protest and meeting with Secretary of State for Wales, Alun Cairns, at which he confirmed payments to victims were the responsibility of Welsh Government;

23 July 2016

I wrote to First Minister for Wales, Carwyn Jones, and Vaughan Gething with response from Alun Cairns, Secretary of State for Wales, who stated that Infected Blood payments were Welsh Government responsibility;

6 July 2016

Meeting with Vaughan Gething, Welsh Health Minister;

27 July 2016

Crowd Justice Appeal set up to raise funds to challenge Welsh Government for a Wales specific consultation and Public Inquiry (details of the funding page and press release are exhibited before me at **Exhibit WITN3988073**)

7 September 2016

Baroness Featherstone met with Andy Burnham;

21 September 2016

Update to MPs and AMs;

29 September 2016

Attended Bad Blood Film organised by Jason Evans with Baroness Featherstone and met Lord David Owen and Professor Edward Tuddenham;

14 October 2016

Welsh Government survey re financial support sent to all beneficiaries;

31 October 2016

Baroness Featherstone and myself met with Professor JP Allain in the House of Lords;

1 November 2016

Baroness Featherstone met with myself and Michael Imperato Watkins and Gunn to decide critical pathway to public inquiry;

25 January 2017

Welsh Assembly Debate – voted unanimously in favour of UK-wide public inquiry;

23 March 2017

Written Statement on Welsh Government Financial support for those affected by contaminated Blood following NHS treatment – transfer to Wales Infected Blood Support scheme;

21 April 2017

Lord O'Shaughnessy's reply to Julie Morgan containing refusal to hold a public inquiry;

15 August 2017

Consultation meeting with Welsh government and Welsh patients confirms demand for Judge led public inquiry and not 'Hillsborough' type panel;

23 November 2017

Meeting with Vaughan Gething, Welsh Health Minister;

11 July 2017

Contaminated Blood Debate;

11July 2017

Theresa May announced that a Public Inquiry would be held into the Contaminated Blood Scandal;

13 March 2018

Statement by Vaughan Gething - Update on the UK Inquiry on infected blood;

26 April 2018

Haemophilia Wales response to Infected Blood Inquiry consultation regarding the Terms of Reference submitted to the Inquiry. A copy of that submission is exhibited above at **Exhibit WITN3988010.**

16 May 2018

Julie Morgan writes to Vaughan Gething regarding concerns relating to the IBD Project Board and Haemophilia Society involvement;

August 2018

Lobbying of Welsh MPs and AMs not to adopt Special Category Mechanism criteria as England for enhanced Stage 1 payments. Petition sent to Welsh Government by English campaigning group with 155 English signatures and 2 Welsh signatures;

August 2018

Contacted all Welsh MPs to ensure they supported a Judge led public inquiry and not a Hillsborough type Inquiry with a panel as Diana Johnson and Peter Bottomley of the APPG were proposing;

14 May 2019

Plenary Oral Questions on 'Support Available to Haemophiliacs and their families' by Mick Antoniw to Mark Drakeford. Also, question from Janet Finch Saunders regarding longer lasting haemophilia treatment which then prompted communication with APPG and Bernard Hanson/ Haemophilia Society;

17 May 2019

Haemophilia Wales writes to Vaughan Gething and Catherine Cody Welsh Government re financial support;

June 2019

Briefing to AMs and MPs - Mick Antoniw to APPG;

1 July 2019

Mick Antoniw to Diana Johnson;

19 July 2019

Watkins and Gunn write to Vaughan Gething setting out proposals for interim financial support to include widows and widowers;

5 August 2019

Vaughan Gething reply to Michael Imperato re financial support;

February 2020

Wrote to New Secretary of State for Wales, Simon Hart, and Under Secretary David Davies MP (Monmouthshire) regarding interim parity of support and requesting a meeting.

14) Describe the response (if any) that you received to the activities described in paragraphs 12 and 13, identifying who responded, when they responded and what the response was.

1. I do not have anything further to add in this Section as the response is covered above.

15) What involvement have you had with the media as part of your campaigning activities? Identify if you are able, the media outlet and the time frames of the media output and outline the nature of your involvement.

1. Exhibited before me at **Exhibit WITN3988074** is a Schedule of Media Activities which provides examples of the extensive media coverage of my work.

Section 6 Complaints to the police or regulatory bodies

16) Provide details of any complaints that you have made to:

a) The police

b) An ombudsman

c) A regulatory body (i.e. the general medical council)

Stating when the complaint was made, whether and if so to what extent it was investigated and what outcome of the complaint was.

1. I do not have anything further to add in this Section as the response is covered above.

Section 7 Litigation

17) Have you been involved in any litigation relevant to the inquiry's terms of reference? If so,

a) Who was the litigation against?

b) In which jurisdiction did the litigation take place?

c) What is your understanding of the issues involved in the litigation?

d) What is your understanding of what information was obtained during the litigation?

e) What was the response of any defendant to the litigation?

f) How was the litigation conducted?

g) What was the outcome of the litigation?

1. In March 2016 Haemophilia Wales Trustees and I had concluded that we needed legal advice on how to achieve improved financial support for victims in the short term and a public inquiry in the longer term. I contacted local Barristers at 30 Park Place in Cardiff but we could not afford to pay for a consultation. I asked if they knew of any solicitors who would help free of charge and they suggested Michael Imperato. Michael was extremely helpful and met with myself and Haemophilia Wales Trustees to establish what could be done to pressurise Government into addressing the ongoing issues of support and to achieve a public inquiry.

Section 8 Other Inquiries

18) Describe any involvement that you have had with any other inquiry (such as Archer, Penrose or Lindsay)

1. I do not have anything further to add in this Section as the response is covered above.

Section 9 Haemophilia Society

19) Describe any involvement that you have had (other than as a member) with reference to the Haemophilia Society

1. The South Wales Haemophilia Group was a local group and part of the UK Haemophilia Society, not an independent charity. Funds raised locally had to be sent to the Haemophilia Society and members felt that the funds were not being used to support people in Wales. In 1999 Devolution for Wales and the Welsh Assembly Government was established. The relationship with the Haemophilia Society and the Macfarlane Trust continued to grow more fractious.

2. On 10 September 1999 there was an open meeting at the University Hospital of Wales. Karen Pappenheim and Chris Hodgson attended from the Haemophilia Society UK. The South Wales Haemophilia Group voiced concerns that the Haemophilia Society was not being proactive campaigning for a HIV/hepatitis C public inquiry.

3. When asked what action the Haemophilia Society were involved in regarding this we were told by the Haemophilia Society 'Nothing active as at present it has all gone quiet'. A founder member of the Birchgrove Group, Paul Jenkins, had died in 1997 leaving a young widow and family. Paul's mother Pat had been a founder member of the South Wales Haemophilia Group so the family had a long history in both supporting families with haemophilia. This was a turning point. There was no faith in the Haemophilia Society, it was viewed as being remote and out of touch.

4. South Wales Haemophilia Group was registered as an independent charity in 2003 and as a committee member I continued to fundraise and help to organise events primarily for newly diagnosed victims and families with children. The campaigning side was then done by Gareth and Haydn Lewis, David Morgan and GRO-A but by 2010 they and my cousin had died. I decided I should apply to become a Haemophilia Society Trustee to influence the Society GRO-C but also as someone who had witnessed the deaths of so many friends and family through infected blood.

5. I felt I could bridge the gap between the Haemophilia Society's inability to deal with the haemophilia community as whole rather than the haemophiliacs infected with contaminated blood as a side issue. When I became a Trustee in 2011 the Chief Executive was Chris James. Chris was well liked but lacked direction from the Board. The Board consisted of a Resources Committee and they held separate meetings. This is where the Society's direction was decided. Lord Morris, President of the Haemophilia Society, was in daily in contact with Chris James. I felt the Board lacked direction and didn't seem to have much interest in, or had given up on, contaminated blood. The feedback from Welsh MPs at the time was much the same. Owen Smith Pontypridd MP, my cousin Leigh's new MP, was enthusiastic about our cause and got on well with Lord Morris. He commented that he and all the Welsh MPs would attend APPG's all fired up and ready to go but they were met with Chris James and some new initiative so there was no clear message from the Haemophilia Society.

6. The Haemophilia Society was receiving £100,000 from the Department of Health at the time following the Archer recommendations and I believe that this is why they would not campaign on contaminated blood. I attended a meeting with Dan Farthing, Policy and Communications for the Haemophilia Society at the time, with Diana Johnson and Jason McCartney who was another MP very focused on contaminated blood and how his constituents were affected. He made it clear he was not interested in supporting the work of the Haemophilia Society and its new initiatives and was only interested in supporting his own constituents who had received infected blood.

7. A Charity Evaluation Report was undertaken by the Society at a cost of £16,000 and the result was the Society should consider whether or not to continue campaigning on contaminated blood. As a Haemophilia Society Trustee, I attended a World Federation of Haemophilia workshop in Paris between 12 and 15 May 2011 where I met with Brian O'Mahony who presented on Advocacy in Action and lobbying campaigns. I also met Bruce Evatt who was a Haematologist working at the Centre for Disease Control in Atlanta USA. He said that in early 1982 he received a report that a haemophiliac had been infected with pneumocystis pneumonia and by July 1982 three haemophiliacs had contracted AIDs. At the end of 1982 a child who had received a transfusion had contracted HIV. Bruce presented this data at the World Federation of Haemophilia Congress in Stockholm in 1983. This can be seen on Bruce Evatt's YouTube video (https://www.youtube.com/watch?v=G4mFmwmCXSw) and his paper 'The Tragic History of Aids in the Haemophilia Population' is exhibited before me at **Exhibit WITN3988075**.

8. Exhibited before me at **Exhibit WITN3988076** is the Advocacy in Action and Concepts in Factor Replacement Course Report dated May 2011.

9. I went to the European Haemophilia Consortium in Budapest where I met Susan Warren from Scotland. When Bernard Manson replaced Liz Rizzutto there was a reorganisation of the Society to make it more effective but Bernard had no understanding of haemophilia and particularly contaminated blood. My suggestions were in-line with how I had worked in Wales - contacting all the Haemophilia Centres, contacting all known members, setting up local groups. I followed what had been done by Brian O'Mahony in Southern Ireland where they had a model Haemophilia Society. I visited Ireland along with Bernard Manson but unfortunately the Irish model was not what Bernard wanted.

10. Dedicated long standing staff such as Nigel Pegram who was providing invaluable support as a Benefits Advisor, and Tom Bradley, Membership and Administration, for over 20 years and Rachel Goodkin, Finance and Office Administration, were replaced with new staff and re-structuring began. Nina Benscher was recruited for fundraising at about the same time Susan Warren and the Scottish Management Committee were trying to register as an independent charity. Susan told me at a Haemophilia Alliance meeting that the registering of the charity was being prevented by Bernard Manson and Nina Benscher. The Board had not been told about this and I raised it because the Haemophilia Society would not lobby Westminster MPs let alone Scottish.

11. When I became a Haemophilia Society Trustee I was surprised that there was a Resources Committee consisting of Board members who made the decisions about the Board's direction. The Resources Committee always met prior to the Trustee's meetings.

12. Chris James' job was made unbearable and he was forced to leave and was replaced by an interim CEO Rachel Youngman in 2013. I attended a meeting with Rachel together with Bernard Manson, Liz Rizzutto and Rowena Jeacock at the Department of Health about continued funding of the Society.

13. Liz Carroll became CEO in January 2014 and she had been interviewed by the Resources Committee. My relationship with the Haemophilia Society deteriorated further as Liz had no concept of what was needed in such a complex charity as she had previously worked in Breast Cancer. She was focused on fundraising and had no understanding of the contaminated blood community. Kate Kahir, Great Ormond Street Paediatric Haemophilia nurse, and co-opted Trustees decided the direction and she had no sympathy or understanding of contaminated blood issues and had not looked after anyone with it. One of the comments made by Kate Kahir was '*why do they need Psychological support? So they can moan about what's wrong with them?*'

14. I did not agree with the Haemophilia Society's aggressive fundraising tactics which involved contacting bereaved families for support, sending collection boxes to very elderly bereaved family members and pressurising them to send funds to them.

15. Below is a timeline of events occurring during my relationship with the Haemophilia Society:

2011

Charities Evaluation Report;

23 January 2012

Lynne Kelly Report to Haemophilia Society Board of Trustees (**Exhibit WITN3988077**);

9 March 2012

Lynne Kelly Report to Haemophilia Society Board regarding Centre Visits (**Exhibit WITN3988078**);

October 2012

Haemophilia Society Draft Briefing paper to APPG on Haemophilia and Contaminated Blood (**Exhibit WITN3988079);**

End of 2012

Haemophilia Scotland formed as independent Charity, previously Scottish Management Committee, but objected to calls for a UK public inquiry as Penrose was ongoing. Exhibited before me at **Exhibits WITN3988080 and WITN3988081** are letters from the Scottish Management Committee which illustrate that Haemophilia Scotland was not supportive of another Inquiry;

23 January 2013

Lynne Kelly report to Haemophilia Society Board of Trustees **(Exhibit WITN3988082);**

10 March 2014

Lynne Kelly emails to Liz Carroll CEO Haemophilia Society and Board of Trustees regarding Haemophilia Society's lack of direction **(Exhibit WITN3988083);**

27 March 2014

Emails between Haemophilia Society and Lynne Kelly regarding a letter from Macfarlane Trust beneficiaries and reply from the Haemophilia Society not being discussed at the 19 March Board Meeting. These emails are exhibited before me at **Exhibit WITN3988084**;

8 April 2014

Alistair Burt meeting at House of Commons to provide update on where he was with the PM and to collect evidence for YouGov Survey organised by Nadhim Zahawi MP about financial support, medical support, Trusts and apology from PM;

June 2017

A protest had been arranged outside the Department of Health, Richmond House, Whitehall and the presentation of a petition to No 10 demanding a public inquiry. It was the day of the Opening of Parliament and the Queens Speech. Haemophilia Wales had arranged a coach from Wales with affected families. We had arranged media coverage by S4C and ITV who were filming about the impact of infected blood on Welsh families. The coach had to be cancelled as riots had been planned due to it coinciding with a Grenfell Tower march thorough London.

There was no Haemophilia Society representation at the Protest outside the Department of Health, Richmond House. Most of the media coverage was provided by ITV Wales and S4C's Ian Edwards who produced the Wales This Week and Y Byd ar Bedwar film with Welsh patients and families with GRO-A, GRO-A GRO-A Janet Morgan, and Judith Thomas. The Haemophilia Society publicised this protest as one of theirs with campaigners but there was no acknowledgement of Haemophilia Wales' involvement;

Wales was excluded from the presentation of the letter to No 10 as I was told by the Haemophilia Society that there were only limited spaces allocated by No 10 to present the petition demanding a public inquiry and all the spaces had been filled. Tim Wratten, a bereaved son and campaigner, had been selected to present the petition. His dad and uncle were both haemophiliacs infected with hepatitis C. Tim's uncle, the late Steve Wratten, was previously a Trustee of the Haemophilia Society and I knew him as he was a patient representative at the Haemophilia Alliance meetings when he was awaiting a liver transplant. Tim kindly offered to give up his place to a Welsh representative who was attending the Protest;

2018

Haemophilia Wales and Haemophilia Society meet at National Assembly for Wales. A note of this meeting is exhibited before me at **Exhibit WITN3988085.**

At the APPG meetings in Parliament there were continued problems with the Haemophilia Society providing the secretariat, and Haemophilia Wales being excluded from the circulation list despite my regular attendance at meetings;

2018

Continued issues with the Haemophilia Society misinforming Welsh MPs about treatment in Wales.

Section 10 Trusts and Schemes

20) Describe any involvement that you have had (other than as a beneficiary) with any of the trusts and schemes established to provide financial assistance

1. My involvement with Infected Blood Support has, over the years, included: gathering evidence from patients and families about their dealings with the Macfarlane Trust, Skipton Fund and Caxton Foundation and then relaying to MPs, Assembly Members and Welsh Ministers the patient's experiences and the ongoing difficulties of contacting the Trusts, Trusts not returning calls , constantly having to fill in forms and when this has been done the goal posts are moved and no guidelines in place.

2. Many widows in Wales had taken part in the 2012 Macfarlane Trust 'Partners and Needs' Survey but as far as I am aware no grants were allocated following this consultation.

3. Assisted beneficiaries in Wales were having difficulty accessing payments from the Macfarlane Trust, Skipton Fund and Caxton Foundation. Jan Barlow, Chief Executive, was always very unhelpful and dismissive. I spoke to Rev Tanner in 2014 regarding my concerns about the Macfarlane Trust. A letter had been sent to the Haemophilia Society by GRO-A GRO-A and other beneficiaries including beneficiaries in Wales. A summary of the letter presented to the Haemophilia Society Board of Trustees by Chair Bernard Manson is exhibited before me at **Exhibit WITN3988086**. I continued to ask everyone in Wales to contact myself about issues relating to the Trusts and we then lobbied MPs and Welsh Government via Assembly Members and the Cross Party Group to address these difficulties. Alistair Burt concluded that 'the MFT was not fit for purpose'.

4. My MP at the time was Jonathan Evans (Cardiff North) and he attended a meeting with Jan Barlow and Roger Evans. Exhibited before me at **Exhibit WITN3988087** are the notes of this meeting. Nick Fish from the Skipton Fund presented Skipton Fund data at the Hepatitis C Workshop I attended in December 2013 (notes exhibited above).

5. I used the experiences of Trust beneficiaries in Wales and my own direct experience of dealing with the Trusts and the lack of financial support for beneficiaries to lobby Welsh Government for a consultation on Infected Blood support. This resulted in the establishment at the Velindre Trust of the Wales Infected Blood Support Scheme (WIBSS). With WIBSS being established they were able to provide beneficiaries with a single point of contact, face to face meetings, welfare and benefits support and psychological support.

6. Despite Jackie Doyle Price, the then Parliamentary Under Secretary of State for Health, being informed by Haemophilia Wales and other campaigning groups at APPG meetings that the Macfarlane Trust (MFT) reserves should be divided between Macfarlane Trust beneficiaries, the reserves and remaining assets were transferred to the Terence Higgins Trust (THT) in December 2018. I contacted David Barlow who was appointed as Macfarlane Beneficiary Support Manager on behalf of Welsh beneficiaries who were seeking support. Exhibited before me at **Exhibit WITN3988088** is David Barlow's reply of 14 January 2019 saying they were deciding the best way to support beneficiaries and that due to data protection they did not have access to MFT registrant's details except those who had taken out loans from the MFT.

7. Tim Waldron then replaced David Barlow and he confirmed that the THT were in the process of designing a consultation to better understand how beneficiaries wanted to be supported. He spoke to colleagues who dealt with the transfer from McFarlane to THT and they didn't know anything about the Honeycombe Trust. I raised this at the Cross Party Group on Haemophilia and Contaminated Blood and also contacted Catherine Cody, Healthcare Quality, Health and Social Services for the Welsh Government and her reply has already been exhibited in this statement at **Exhibit WITN3988066**.

8. **Exhibit WITN3988089** is the Welsh Infected Blood Support Scheme (WIBSS) Special Category Mechanism (SCM) Wales Viewpoint and opinions: Clinical Perspectives on SCM approach which has been completed by Professor Peter Collins, Cardiff Haemophilia Centre and Vice Chair UKHCDO. This supports Haemophilia Wales's position to not implement SCM in Wales as he says it is causing distress to patients and increased workload and disruption to his counterparts in England who are unable to assess the mental and physical impact of hepatitis C.

9. Myself and Nigel Miller, Haemophilia Wales Trustee, sought advice from Michael Imperato as we were concerned when the WIBSS Project Board was replaced with a WIBSS Management Group. Michael Imperato advised we should not be involved in the day to day management of the scheme and so we withdrew and suggested that WIBSS set up a Stakeholder Group.

This hasn't happened yet, however, I am in regular contact with WIBSS and the feedback from patients is very good. The real issue is that there isn't enough money in the scheme and widows and widowers are excluded, hence why we continue to press the Welsh Government for interim parity with the rest of UK including widows and widowers.

10. Exhibited before me at **Exhibit WITN3988090** is a letter from Lucy O'Brien of Watkins & Gunn Solicitors to Vaughan Gething which sets out what we are continuing to ask for. Sir Brian Langstaff requested interim parity of support for victims on 15 October 2018 and 10 July 2019.

11. On 28 January I attended an inter-ministerial meeting with Julie Morgan and Jackie Doyle Price. I also met with Oliver Dowden at the Cabinet Office.

12. I emailed Simon Hart, Secretary of State for Wales, asking for a meeting. This email is exhibited before me at **Exhibit WITN3988091** together with his extremely disappointing response.

13. Both myself and Mick Antoniw AM and Chair of the Cross Party Group asked for an urgent meeting with Vaughan Gething and proposed urgent interim non means tested support for 37 widows/ers, 44 Stage 2s and 11 co-infected victims in Wales. Vaughan Gething refused to meet with us but agreed to send Welsh Government officials to the Cross Party Group Meeting on 11 March 2020. The officials didn't turn up which was insulting and upsetting to the victims and families in attendance. It was agreed that we should contact the Inquiry and ask Sir Brian Langstaff to intervene by writing to the devolved Governments to ask them what they had done about his request to level up payments since 15 October 2018.

14. On 18 March 2020 I participated in a teleconference with Catherine Cody, Health and Social Services, Welsh Government, Julie Morgan, Deputy Welsh Health Minster and Mick Antoniw Chair of the Cross Party Group to reiterate our demands to level up payments across the UK to include widows and widowers as an interim measure. I have followed up with a reminder email on 25 March 2020 to them and two telephone calls to Catherine Cody who has confirmed Welsh Government have received the figures to level up payments including widows and widowers from WIBSS and the decision is with Welsh Government finance.

15. Exhibited before me at **Exhibit WITN3988092** is correspondence relating to the campaigning activities of Haemophilia Wales Trustee, Tony Summers. Tony had been campaigning throughout the late 1980s and 1990s following his son's infection with HIV and hepatitis C. Tony was in close contact with his MP at the time, John Smith MP for Cardiff and the Vale, and visited Parliament many times for meetings with MPs and Peers. Within this Exhibit is a letter from Baroness Hayman to John Smith MP received on 27 October 1998 which states

that the Government could not make an exception for providing financial support to haemophiliacs infected with hepatitis C but were funding a project developed by the Haemophilia Society aiming to meet the advice and information needs of young haemophiliacs infected with hepatitis C. We would like to know how that money was used by the Haemophilia Society.

16. One of the members of Haemophilia Wales instructed Watkins and Gunn Solicitors in August 2019 to bring Judicial Review proceedings to challenge the failure of the Welsh Government and Westminster Governments to bring scheme payments for Welsh victims up to the level of English and Scottish victims. The Claimant was refused legal aid funding due to the income he received from WIBSS. He has therefore issued Judicial Review proceedings to challenge the legal aid refusal, following which he intends to bring proceedings on the parity issue.

17. Through their respective MPs (Virginia Crosbie MP and Steven Kinnock MP), other members of Haemophilia Wales have raised individual complaints, regarding lack of parity of financial support for victims, with Penny Mordaunt MP, the Paymaster General. Her responses to those complaints are exhibited before me at **Exhibit WITN3988093.**

Conclusion

1. I was aware of the South Wales Haemophilia group through the Haemophilia care my family had received - from my Grandfather through to my cousins. I became more familiar with the group following the birth of my first GRO-C son in 1989. The South Wales Haemophilia Group had been set up by Professor, then Doctor, Bloom, Dentist Christopher Lewis, Haematology lecturer John Giddings and patients GRO-A GRO-A and Pat Jenkins. Pat was the mother of Paul Jenkins who died in 1997 aged 39 as a result of contaminated blood. Other members of the group were GRO-A whose two sons died aged 23 and 30, GRO-A whose son died age 31 and GRO-A sister of GRO-A whose son died aged 32, and GRO-A and GRO-A

2. This group, with others, were consistent fund raisers for the Haemophilia Society and I became an active member of the group helping with the organisation of the children's parties and fund raising generally. The group however were increasingly frustrated about the lack of understanding of their position from the Haemophilia Society.

3. GRO-A and GRO-A's son GRO-A died in 1992 at the age of 21 through HIV contaminated blood GRO-A kindly gave me some of her son's toys and books and in playing with the toys with my own children this tragedy increasingly played on my mind. As a 30 year old mother GRO-C I wondered how I would cope with a death of this nature.

4. Their family stories were at odds with the experience in my family where my Grandfather, who was a mild to moderate haemophiliac had worked underground and in the later part of his working life on the railways, had fathered seven children and lived until he was 76. His brother, also a haemophiliac, lived until he was 91.

5. During this period, 1989-1994, I also became friendly with the patients themselves through regular visits to the Haemophilia Centre. I met many patients who had been infected with HIV and of those Gareth Lewis, David Edwards and Paul Jenkins, who were the founder members of Birchgrove Wales, which became the national Birchgrove Group in 1993. It was then that I met David Morgan, GRO-A GRO-A and GRO-A, all of whom subsequently died as a result of contaminated blood. It was evident every family had a story that had never been told and these were people grieving the loss of their children or young men and struggling to cope with the effects of HIV or hepatitis. A common theme was that people, while not directly 'told' to keep quiet about the circumstances of their child's death or their infection, were certainly encouraged not to speak of it. They became deeply affected by the stigma of association with AIDs/HIV and angry that there seemed no one speaking on their behalf.

6. This was a confusing time, for despite the infection and increasing levels of illness, the history of the Haemophilia Centre was bound tightly with the excellent care all the haemophiliacs felt they had received and the very strong feelings of friendship with Dr (Professor) Bloom. I also considered my haemophiliac cousins to be very lucky to have avoided contaminated treatment. It was not however until 1994 that they were told that whilst they had escaped HIV infection, they had been infected with hepatitis C.

7. During this period, as young parents, we found it strange that when GRO-C children required treatment the Centre were always reluctant to administer Factor 8, preferring to plaster and immobilise the damaged joint and Factor was only used as a last resort. We started to have concerns about the approach which we thought was based on considerations of cost and we raised those concerns with Dr Dasani, the Cardiff Haemophilia Centre Associate Specialist. Dr Dasani, who we later understood had previously worked at the Treloar School Haemophilia Centre, and had first-hand experience of contaminated blood, had concerns that the Factor 8 was not being heat treated and that batches of treatment potentially remained unsafe. He had adopted the technique of plastering to avoid putting patients at risk. This started to raise questions in my mind as to the actual extent of the contaminated blood story, how accurately the events had been recorded and if this was an ongoing problem.

8. Professor Bloom died in 1992 and my cousins and David Thomas were told of their infection with hepatitis C in 1994 when I was pregnant with my third son. Up until this point, my cousins had lived a normal life, but as I understood more about the contaminated blood story from the members of the South Wales Haemophilia Group and the campaigners at the Birchgrove Group, I realised the story was far from straight forward and was to some extent still evolving.

9. My cousin died in 2010 after a long and traumatic illness through which we experienced all of the short falls in specialist Hepatology care, the lack of appreciation of the effects of contaminated blood by general nursing staff, the stigma the patient and family felt and the horrific reality of death from liver failure due to liver cancer . It was at this point we realised our family were just the next, soon to be forgotten, deaths on a growing list which started with the GRO-A GRO-A the first Haemophiliac to die of Aids in Cardiff in 1985 and his brother GRO-A in 1991. The realisation we were just 'another' family made me all the more determined to do something. It was after my cousin's death in 2010 that we joined the by now diminishing group of campaigners and we became a vocal banner waving group of protesters at Westminster and The Welsh Assembly.

10. While there were a number of recognisable steps in my transition from mother to charity volunteer, there were four people I met that left a lasting impression on me and influenced my approach to dealing with this issue. Aside from Julie Morgan who has consistently supported our cause since the 1990s both as an MP and an Assembly member, Della Hirsch, Lord Alf Morris, The Reverend Tanner of St Botolphs Church, Bishopsgate, London and Brian O'Mahony, Chief Executive of The Irish Haemophilia Society.

11. I met Della Hirsch as patient representative at the Haemophilia Alliance meetings. Della was a significant supporter and donator to the Haemophilia Society and was angry about the lack of progress following the Archer Inquiry. Her haemophiliac son, Nick, had contracted hepatitis C, and Della, wanted answers from the Department Health and the UKHCDO. In listening to her complaints to the Society about their ineffectiveness of campaigning on contaminated blood and reflecting on the disconnect between the Society and the members in South Wales who had experienced similar problems, I was more driven to get answers. We became good friends and when her son died, her sister, Lynne Featherstone was MP for Woodgreen and Hornsey. When she became Baroness Lynne Featherstone we started working together on campaigning for a public inquiry. Her influence opened doors at the Department of Health which would never have happened and led to the Department of Health's Self Sufficiency in Blood and Blood Products 1973-1991 being withdrawn for use.

12. I met Lord Alf Morris, President of the Haemophilia Society, at Lobbies and Protests in Westminster. As the first Minister for the Disabled and the champion of the contaminated blood issue he was ringing the Haemophilia Society daily but the Haemophilia Society were not on the same page at all and saw no urgency to act. He brought about the Archer Inquiry almost singlehandedly and continued to get his contaminated blood bills through the Lords despite consistent opposition until his death in 2012.

13. I first met Brian O'Mahony, the Chief Executive of the Irish Haemophilia Society, when, as part of the World Federation of Haemophilia, he chaired the 'Advocacy in Action' workshop in Paris. I was invited as a Haemophilia Society Trustee with Dan Farthing who was Policy and Communications coordinator at The Society. The workshop set out a very clear strategy to bring about change through advocacy, the objective was to achieve a stronger voice for bleeding disorders globally. Simply put, he explained advocacy is the process of influencing key individuals, decision makers and organisations to bring about change. He also explained how to generate and use qualitative and quantitative data in the assessment of the effectiveness of that change.

14. In highlighting the need to collaborate with clinicians and politicians to build networks for change, it was made clear that decision makers use confusion as a reason not to take action. The message was clear that there was a route map to achieve change but it could only be delivered with collaboration, cooperation and with 'one voice'. As previously exhibited before me at **Exhibit WITN3988074** is the 2011 Advocacy in Action report to The Haemophilia Society Board.

15. I had read the findings of the Lindsay Tribunal and reviewed the settlement achieved in Ireland. In speaking to Brian O'Mahony he felt that the success in getting recognition and compensation for the haemophiliacs who were affected by contaminated blood was in some part due to the recognition by the Irish Government of the case made by transfusion victims.

16. Beyond seeing how effective a well-run Society could be, his analysis of the outcome of the Lindsay Tribunal gave me the clear impression that any representation made to Government had to be all inclusive, representing the wishes of transfusion patients as well as haemophiliacs and all the affected including widows/widowers. The conclusion was given that due to the entrenched nature of the UK Government, without a full public inquiry there was no viable route available to bring the matter to a conclusion.

17. As a Trustee of the Society I subsequently visited Ireland in March 2012 and witnessed first-hand how a Society could be inclusive, representing all ages and standpoints and be very

effective and persuasive in its communication with all the stakeholders. I became a constant advocate for the UK Society to adopt 'the Irish model,' as all the components of an exemplar service provision were already in place. The Society however were unpersuaded and did not implement any of the recommendations.

18. After my cousin's death in 2010 and throughout my time at the Haemophilia Society, I maintained contact with the various campaigning groups and was active in a number of protests and awareness campaigns and continued to campaign for a public inquiry. I had hoped to bring the information I learnt into the Society and help inform their strategy.

19. The turning point for me personally was the realisation that not only were the Society not going to take an inclusive approach; I was shocked to find that the Haemophilia Society saw the separation of the older 'contaminated' haemophiliacs as necessary to protect young families from becoming traumatised. From my family history I envisaged the Society as one entity supporting the old and young alike because I saw haemophilia as a 'generational thing' passing through a family. Some trustees voiced at board meetings that campaigners were a noisy irrelevance, but there was also in my view a feeling of superiority and an unwillingness to collaborate with campaigning groups and the Hepatitis C Trust. I felt this was strange as the campaigning groups would not have been set up if the Haemophilia Society had done its job. An example of this was the failure of the Society to see the importance of a Hepatitis C treatment workshop in the Department of Health in December 2013. The Chair could not attend and asked one of the Trustees to telephone in. I saw the Agenda and given the desperation I knew many people were experiencing having failed hepatitis C treatments three or four times I felt it could be an important meeting as new Interferon free hepatitis C treatments were being discussed by leading UK Hepatologists. I realised that if the Society were not going to engage and cooperate with other organisations who were better informed than themselves and to build a 'One Voice' approach, they would as a result become ever more ineffectual as an organisation.

20. On 26 Feb 2014 the Macfarlane Trust beneficiaries wrote to the Society following the adjournment debate of 29 October 2013 at which The Macfarlane Trust were presented as not being fit for purpose. Bernard Manson, Chair of the Society, responded to the letter without regard to the general feeling in the community being voiced by the Trustees that the criticisms were justified. It had been well documented that the beneficiaries of the Trusts were being severely disadvantaged with access to the funds proving difficult and trust managers seeing it as their job to restrict access to funds as much as possible. As previously exhibited before

me at **Exhibit WITN3988084** is my 27 March 2014 email to Bernard Manson regarding the Adjournment Debate in 2013.

21. At this time I had a long conversation with Reverend Tanner regarding The Macfarlane Trust. I found he was shocked at the way in which the Trusts were acting and the distress their actions were causing.

22. Reverend Alan Tanner had been The Chair of the Haemophilia Society from 1975 -1997 and had been interim President of the World Federation of Haemophilia. Reverend Tanner's haemophiliac son died in 1998 as a result of HIV. He founded the Memorial service held annually at St Botolph Church and had ministered to many of the families who lost loved ones in South Wales and throughout the UK. He was unaware of the scale of the problem with the Trusts in the UK and the lack of strategy and unwillingness of the society to engage on behalf of the affected community. I felt at that point the scale of the inertia around the Society was so great it would be impossible for me to move them. He said if 'I was driven' to do something and if this was 'a calling' I should act on it, which struck a chord with me. It was following this conversation I felt that there was no more I could do within the Society and tendered my resignation on 24 June 2014.

23. Haemophilia Wales had been founded in 2003 and subsequently wound down as many of the founding members had died. After my resignation from The Haemophilia Society in 2014 I felt that I should remobilise Haemophilia Wales with the objectives of providing exemplary Haemophilia care, re-engaging with the grass roots membership in Wales and developing the campaign for a public inquiry.

24. From my experience with The Society and my understanding of the work that had been done in Ireland, I felt I had a clear picture of how to put the foundations of a Charity into place. From my involvement in the South Wales Haemophilia Group and Haemophilia Wales I found that mutual support and networking was key. People want to know where their donations are going and what they are going to get out of it. It was evident this kind of charitable support was lacking at a national level and there was a feeling of mistrust of the Society as they had not fought on victims' behalves and were too close to pharmaceutical companies. The Society did not figure in people's lives and most felt there was no charity supporting them.

25. With eleven Trustees' total commitment to collaborating with the clinicians, politicians and any campaign groups that shared our inclusive approach to representing all of the affected and infected community, we sought to secure the best treatment and support available in Wales. The work of Haemophilia Wales is well documented in the statement above but we are

particularly proud to have achieved access to new treatments service provision, psychological and welfare and benefit support before any of the UK nations.

26. If, however, all parties were to have aligned agendas and develop trust and continuity in the objective of getting a public inquiry, we knew there was the absolute need to have 'one voice'. I had learnt the lesson from the Advocacy in Action work shop of 2011 the hard way and understood that 'decision makers use confusion as a reason not to take action' and we decided at the outset the presentation of the need for a public inquiry from Wales would be heard as 'One Welsh voice'.

27. The Archer Inquiry was privately funded and could not compel witnesses to appear or find fault. Importantly any recommendations could be, and were, ignored by Government.

28. The campaign groups were very active in the support for a public inquiry and very effective at lobbying MPs. GRO-A, whom I have known as a campaigner for over 10 years, had mobilised Alistair Burt MP who had a clear understanding of the issues faced and the results of his survey in November 2014 reinforced the need across the community for compensation and a public inquiry. The Department of Health's response was to organise a further consultation focusing on financial support and excluded a public inquiry.

29. Whilst we were lobbying for a consultation due to the problems with the Schemes and Trusts in 2016, The Haemophilia Society were promoting a committee of 22 people to work with the Department of Health to develop a structure of financial support. This response to the Department of Health's proposal was done without consultation and no one agreed with it as a route forward. Importantly the mood of campaigners had now moved on as a younger generation of people had come forward to join the campaign, the children of families torn apart by the effects of contaminated blood, who through social media were better informed.

30. From this response, Haemophilia Wales and other campaigners recognised that there would never be a public inquiry without a legal challenge and in 2016 Haemophilia Wales met Michael Imperato at Watkins and Gunn Solicitors in Cardiff to provide legal advice on a challenge to Government. The public inquiry was and is a UK wide inquiry and under the Inquiries Act required the agreement of all the devolved administrations and as result of the united Welsh position a public inquiry was achieved.

31. The input from Michael Imperato with his public law perspective was very important. In January 2016, following much campaigning, the Department of Health put forward proposals on financial support which were not well received by victims as the living were worse off and

bereaved families were ignored again. It was clear to myself and Haemophilia Wales Trustees that no progress would be made in establishing the truth without seeking legal advice. We had previously sought advice from Thompsons Solicitors in Cardiff but they weren't interested in taking our case forward. I wrote to the barristers at 30 Park Place asking for advice. We could not afford the fees for a conference meeting and I asked for them to recommend a kind solicitor who would see us free of charge. As the only claimant focussed public law solicitor in Wales, Michael Imperato met with us pro bono many times and advised pressing for a Wales Specific Consultation culminating in a UK wide public inquiry.

32. Over the course of 2016 through the Welsh Assembly consultation regarding financial support it became clear to those in Government that were previously unconvinced that a public inquiry was the only solution to the problem, the scale of which was now laid out for every to see.

33. We set up a Crowd Justice page to raise funds to challenge the Welsh Government with a view to then setting a legal challenge for a public inquiry. We reached the target of £10,000. Julie Morgan instigated the Contaminated Blood Debate in The Welsh Assembly in January 2017 where the Welsh Assembly Government voted in favour of holding a judge led public inquiry and went on to ensure that a public inquiry was in the Welsh Labour Party Manifesto. Welsh MPs led by Stephen Kinnock ensured that this was included in the Labour Party Manifesto on 17 May 2017.

34. On 11 July 2018 Theresa May granted a public inquiry, however there was a concerted effort on the part of Diana Johnson and others to lead the community to a Hillsborough type, truth and reconciliation type Inquiry.

35. Owen Smith MP, well thought of by Alf Morris, was a new MP who took on the cause and related to the families. He was responsible for pitching to the Back-Bench Business Committee for the first ever Back Bench Business Debate.

36. My MP, Jonathan Evans, lobbied for new hepatitis C drugs and tried to get a Bill through Parliament on this in 2014 for off patent drugs to be used for new indications. Jonathan was a lawyer, and he advised continued campaigning for Archer recommendations and compensation in line with Southern Ireland. He voted against the Conservative Party twice in his career and once for contaminated blood. He got on well with Alistair Burt and Lord Morris and I was invited to Lord Morris' reception with Jonathan Evans.

37. My hopes for the future are that the Inquiry can get to the truth about what happened and will recommend suitable compensation for infected and affected families similar to the Irish

settlement which includes Health Amendment cards to ensure priority access to healthcare needs.

38. Education and understanding of the contaminated blood disaster is essential for all medical staff to ensure that the infected blood community do not have to continue to experience the stigma which continues to leave a lasting memory on both living and bereaved families. Palliative treatments are needed with a care pathway for terminally ill infected blood patients to ensure they are not kept waiting on a trolley without a bed as often happens. When no further treatment options are available funds should be available for holistic treatment or off patent drugs for new treatments when other treatments have failed. In the longer term, I hope that the UK Public Inquiry will lead to an International Inquiry to give a global perspective on how and why this happened.

Statement of Truth

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

Signed GRO-C

Dated 30.7.20