Witness Name: Lynne Kelly

Statement No:WITN3988001

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#### **EXHIBIT WITN3988010**

This paper has been prepared by Haemophilia Wales and The Cross Party Group on Haemophilia and Contaminated Blood.



Registered Charity No: 1158941

### Cross Party Group on Haemophilia and Contaminated Blood



National Wales

Haemophilia Wales is an independent charity in Wales

Chair: Lynne Kelly

Registered charity number 1158941

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#### **Executive Summary**

This document sets out a brief history of the contaminated blood disaster from a uniquely Welsh perspective. From the establishment of The Birchgrove Group and the South Wales Haemophilia Group, as self help support groups leading to the establishment of Haemophilia Wales in 2003 and The Cross Party Group on Haemophilia and Contaminated Blood at the Welsh Assembly in 2012. Through the tragic diagnosis of the UK's first HIV positive Haemophiliac in Cardiff in 1983, to the establishment of one of the UK's first Comprehensive Care Haemophilia treatment centres in Cardiff, up to the Welsh Governments current initiative which is leading the UK in the attempt to eradicate Hepatitis C.

We recognise the initial phase of The Inquiry is to seek the views of the affected community to define the Terms of Reference and what period of time should be examined. This document offers an overview of the results of the consultation with the Members of Haemophilia Wales and The Cross Party Group on Haemophilia and Contaminated Blood in Wales and builds on the key points made in our submission to Department of Health and the Cabinet Office in 2017 to ensure a Welsh voice in the Inquiry.

There has been a long history of campaigning in Wales for a Public Inquiry and for the full disclosure of data and documentation not covered in the independent Archer Inquiry and the Penrose Inquiry. There is also considerable anger over the deliberate destruction of documents and the inaccurate recording of the history by the Department of Health to prevent a clear understanding of the facts, further frustrating the understanding of the full extent and cause of the tragedy and dividing the community.

Despite the history of campaigning and the disclosure through the Penrose and Archer Inquiries there remains much for this Inquiry to uncover:

- Whether the UK blood supply was compromised as a result of commercial interests, and did those commercial interests take precedence over patient safety and lead to misconduct by the responsible bodies.
- How the blood policy, designed to react to the unfolding tragedy, developed and why the known risks were left unmanaged and patients left to contaminate other family members.
- To investigate whether the Secretary of State for Health entered into compromise agreements with those infected with HIV without disclosing known risks of Hepatitis C.
- Why the UK Government and UK Haemophilia Doctors were slow to react to warnings of safety and to Self sufficiency in Blood and Blood Products.
- How the various trusts set up to alleviate the suffering of the affected were used to further divide and alienate the users.
- In the aftermath of the disaster how the responsible bodies should now react and how restitution can be made for so many affected lives.

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#### Introduction

Haemophilia Wales and the Cross Party Group on Haemophilia and Contaminated Blood fully support the establishment of a Statutory, Judge led Public Inquiry.

In January 2017 the Welsh Assembly Government voted unanimously in favour of a UK wide Public Inquiry into contaminated blood. <a href="https://yoursenedd.wales/debates/2017-01-25-5-debate-by-individual-members-under-standing-order-11-21-iv-contaminated-blood">https://yoursenedd.wales/debates/2017-01-25-5-debate-by-individual-members-under-standing-order-11-21-iv-contaminated-blood</a>

We believe The Inquiry should be a full Public Inquiry under the Inquiries Act 2005 with the power to compel witnesses and to ensure full disclosure of documents.

In November 2017 Haemophilia Wales and the Cross Party Group on Haemophilia and Contaminated Blood made a submission to the Department of Health for a Statutory, Judge led Public Inquiry.

We remain completely committed to ensuring that victims in Wales have an effective voice in the UK wide Inquiry.

#### Haemophilia Wales

Haemophilia Wales was established as an independent charity in 2003 and provides information support and advocacy to over 300 members in Wales.

We are affected volunteers, independent of the UK Haemophilia Society. Our Trustees and members have been campaigning for justice since the first Haemophiliac in the UK to contract the HIV virus was diagnosed in Cardiff in 1983.

Six of our original committee members have died as a result of contaminated blood.

#### **The Cross Party Group**

The Cross Party Group on Haemophilia and Contaminated Blood at the Welsh Assembly was formed to raise awareness of the issues affecting the community of infected patients and to improve provision of treatment and support across Wales.

Julie Morgan AM is 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 currently as an Assembly Member. Julie Morgan, Cross Party Group members and Welsh MPs continue to be a strong political voice in the continuing search for truth and justice for the affected community.

#### **Background**

March 2015: Prime Minister David Cameron apologised for the contaminated blood disaster on the same day as the Penrose Inquiry findings were announced.

December 2016: Vaughn Gething Welsh Cabinet Secretary for Health wrote to Lord O'Shaughnessey in support of a UK wide Public Inquiry

January 2017: Welsh Assembly Government voted unanimously in favour of a full UK wide Public Inquiry into contaminated blood

March 2017: Julie Morgan AM, Chair of the Cross Party Group on Haemophilia and Contaminated Blood wrote to Lord O'Shaughnessey calling for a Public Inquiry in order to establish the facts relating to the contamination of the blood supply and to enable the families of the affected to understand how this disaster occurred and could have been prevented.

April 2017: Lord O' Shaughnessey replied refusing to hold a Public Inquiry. Subsequently a letter of Claim was sent by our Welsh Legal team with a view to securing a Judicial Review of the response.

July 2017: Prime Minister Theresa May announced a UK wide Public Inquiry into contaminated blood.

August 2017: Haemophilia Wales and the Cross Party Group on Haemophilia and Contaminated Blood made a submission to the Department of Health for a Statutory Judge led Public Inquiry November 2017: Haemophilia Wales and the Cross made a submission to the Cabinet Office for a Statutory Judge led Public Inquiry.

#### **Extent of Infections in Wales**

#### Hepatitis C

316 people have been infected with Hepatitis C in Wales, of those 55 were also infected with HIV.

It is *estimated* that 96 people have died as a result of infected blood supply in Wales. It is stressed that this is an estimate due to the way mortality data is registered and interpreted.

#### **Extent of infection in Wales**

(Data provided by the Wales Infected Blood Support Scheme)

Haemophilia	Alive	Deceased	Total
HIV/Hep C	16	13	29
Stage 1			
HIV/Hep C	1	20	21
Stage 2			
HIV/Wife	1		1
Hep C Stage 1	46	12	58
Hep C Stage 2	16	18	34
Total	80	63	114

Blood Transfusion	Alive	Deceased	Total	
Hep C Stage 1	98	16	114	
Hep C Stage 2	72	16	88	
•			1	
Total	170	32	202	

55 people with bleeding disorders were infected with HIV, 15 are alive at the date of preparation of this paper. One infected HIV widow is still alive.

(NB: Those infected with Factor concentrates were re infected every time they received treatment and were exposed to multiple viruses and Genotypes.)

#### Data

It has been extremely difficult to provide 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 has been recorded.

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.

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 of 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.

#### History of campaigning in Wales

inotory or campaging management
1964: The Haemophilia Society UK was registered as an Independent charity
1967: South Wales Haemophilia Group was formed by patients <b>GRO-A GRO-A</b> , <b>GRO-A</b> Fundraising) and clinicians Dr (Professor) A Bloom Haemophilia Specialist, Christopher Lewis Dentist, and John Giddings, Lectures Cardiff University to provide support to patients across South Wales.
During this period Cryoprecipitate and Factor Concentrates were introduced as a treatment for Haemophilia instead of whole blood transfusions and plasma.
1983: In May 1983 the first Haemophiliac in the UK to contract the HIV virus was diagnosed in Cardiff.
1986: Birchgrove Wales was established, a self help group for Haemophiliacs infected with HIV led by Paul Jenkins, Gareth Lewis and GRO-A In 1987 after much campaigning a Social Worker Mary Dykes was appointed and funded by the Welsh Office to support those affected by contaminated blood. (Tim Hunt and Nia Jones later replaced Mary Dykes).
1993: The First Conference organised by Birchgrove was held in the Bloomsbury Hotel in London for HIV positive Haemophiliacs. The National Birchgrove Group was formed with Paul Jenkins, Gareth Lewis, Cady Khudabux and <b>GRO-A</b> . Haemophiliacs with HIV and their families were encouraged to seek support and participate in various events throughout the UK.
1996/97: After a successful lobbying campaign supported by Julie Morgan MP, funding for safe non plasma derived Recombinant factor 8 and 9 was agreed for Wales.

September 1997: Martha Cirino and Melanie Orens were appointed as Children and Family workers at Birchgrove Wales, funded by the Lotteries Charity Board Wales.

December 1998: Birchgrove Wales Committee Chair Gareth Lewis,
Vice Chair <b>GRO-A</b> Secretary <b>GRO-D</b> Treasurer <b>GRO-D</b>
GRO-D
January 1999: Open day at Birchgrove Wales, 110 Caerphilly Rd,
Birchgrove, Cardiff where the National Birchgrove newsletter was
produced and sent all over the UK. <b>GRO-A</b> , Alan Burgess, <b>GRO-D</b>
<b>GRO-D</b> , <b>GRO-A</b> and <b>GRO-A</b> ran the National Birchgrove
Group.
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.  June 1999: The South Wales Haemophilia Group was formed with Gareth Lewis: Chair, GRO-A: Vice Chair, Jan Wallace: Secretary,
GRO-A : Treasurer. Committee members: GRO-A
GRO-A GRO-A GRO-D GRO-A and GRO-A GR
GRO-A and GRO-A , Lynne Kelly. Meetings were arranged with Julie Morgan MP to gain support for a new Comprehensive Care Haemophilia Centre at Cardiff.
10 <sup>th</sup> September 1999: 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 were not being proactive campaigning for a HIV/Hep C Public Inquiry.

When asked what action the Haemophilia Society were involved in regarding this we were told by the Haemophilia Society 'Nothing active as at present its all gone quiet'

21st October 1999: Gareth Lewis, **GRO-A** and Jan Wallace, South Wales Haemophilia Group met Assembly Member Dr Dai Lloyd at the Welsh Assembly to gain support for a Public Inquiry.

20<sup>th</sup> December 1999: Meeting at UHW to discuss Haemophilia Centre accommodation. Committee members included David Morgan, GRO-A GRO-A Julie Morgan MP and Dai Lloyd AM attended with acting Chief Executive Jonathan Davies, Tim Heywood, Professor Alan Burnett, Dr Peter Collins, Heather Cotterell, Dave McGee, Peter Wilson.

December 1999: National Lottery Charity Grant £4475 awarded to Haemophilia Wales

7<sup>th</sup> November 2000: Wrote to all members inviting them to our first AGM and advising them we would be voting as to whether it would be in the interest of the South Wales Haemophilia Group to be established as a local group of the Haemophilia Society or to operate as a separate body Haemophilia Wales.

17<sup>th</sup> November 2000: The Official opening of Arthur Bloom Haemophilia Centre.

29<sup>th</sup> November 2000: AGM vote carried to operate as a separate body as the Haemophilia Society UK was not acting in the interests of the affected community in Wales.

14<sup>th</sup> February 2001: Cross Party Group Reception at the National Assembly for Wales funded by Plaid Cymru. Haemophilia Wales presented their case for compensation for Haemophiliacs.

8<sup>th</sup> March 2001 Contaminated Blood Debate at Welsh Assembly led by Dr Dai Lloyd demanding a Public Inquiry

May 2002: Haemophilia Wales met with Mike Evans Specialised Health Service Commission Wales to ask to support the National Service Specification for Haemophilia.

2003: Haemophilia Wales replaces the South Wales Haemophilia Group and is registered as an independent charity. The existing committee members remain. Mike Evans Health Commission Wales was invited to gather information for the commissioning of Haemophilia services across Wales.

29<sup>th</sup> April 2003: AGM **GRO-A** vice chair and Jan Wallace Secretary stood down. Haydn Lewis was voted in as Secretary.

23<sup>rd</sup> May 2004: Birchgrove Woodland Grove, Stratton Wood in Swindon unveiling of inscribed permanent memorial stone with 1200 trees planted to represent 1200 Haemophiliacs infected with HIV. The memorial continues to be a place of pilgrimage for the community.

By 2010 the six founding members and officers of Haemophilia Wales: Gareth Lewis, Paul Jenkins, GRO-A GRO-A and Haydn Lewis had died, GRO-A was seriously ill as a result of receiving contaminated blood products and the charity could no longer continue to function and its operations were suspended.

2014: Haemophilia Wales was re-established by committee member Lynne Kelly. The current Haemophilia Wales Committee members and Trustees are Lynne Kelly (Chair), GRO-A Helen and John Morris, David Thomas, Tony and Pat Summers, GRO-A Nick Kelly, Richard Gorman. The team remain as committed as their predecessors were to achieving the goals set out by the South Wales Haemophilia Group, Birchgrove Wales and Haemophilia Wales.

#### 2003 to 2018:

Haemophilia Wales has been instrumental in maintaining pressure on central and devolved Governments for a Public Inquiry, new

Hepatitis C treatments and continuing to improve the standards of Haemophilia care across Wales.

- 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.
- The establishment of the Arthur Bloom Comprehensive Care Haemophilia Centre in Cardiff.
- The introduction of Recombinant Factor 8 and Factor 9 in Wales before England.
- Year on year Improvements in financial support and service provision within Wales
- The successful lobbying of the Welsh Health Ministers Edwina Hart, Lesley Griffiths and Dr Chris Jones Chief Medical Officer leading to a review into Haemophilia care and improved payments in Wales.
- The Back Bench Business Debate on Contaminated Blood October 14th 2010 initiated by Owen Smith MP for Pontypridd.
- As member of the Ministerial Task and Finish Group Review into Haemophilia Care in Wales 2011 for the appointment of a consultant Hepatologist at the University Hospital of Wales, specialist Haemophilia Physiotherapy and Psychological support for throughout Wales.
- A supporting organisation to the Cross Party Group on Haemophilia and Contaminated Blood at the Welsh Assembly chaired by Julie Morgan AM.
- A member of the All Wales Advisory Group on Inherited Bleeding Disorders Chaired Welsh Health Specialised Services

Commission (WHSCC) with Haemophilia Doctors, Nurses, Physiotherapists, Haemophilia Psychology and social worker support, patient representatives from all over Wales.

- Haemophilia Wales has been instrumental in securing:
  - 4- Haemophilia Psychologists to serve the patients at the Cardiff, Swansea & Bangor Haemophilia Centres.
  - 3- Haemophilia Physiotherapists to serve the patients at the Bangor, Swansea and Cardiff centres.
  - 1- Haematologist to serve the patients at Swansea.
  - 1- Hepatologist to serve the patients at Cardiff.
  - 4 Fibroscans machines to allow monitoring of Fibrosis for Haemophilia patients with Hep C.
- The Interim Commissioning Policy for Sofosbuvir the Interferon Free Hepatitis C treatment for the severely ill.
- Improvements in Social Work support in Wales
- September 2015: 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 for Hepatitis C treatments.
- 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 in Wales have now been treated with Hepatitis C treatments ahead of England and there is currently no waiting list for anyone needing treatment for Hepatitis C.
- 7<sup>th</sup> February 2016: Carwyn Jones 1<sup>st</sup> Minister, Welsh Assembly wrote to Jeremy Hunt regarding the shortcomings of new proposals on infected blood support in England.

- 12<sup>th</sup> April 2016: Contaminated Blood Debate and Protest at Parliament: Haemophilia Wales and Welsh MPs.
- 6<sup>th</sup> July 2016: Haemophilia Wales met with Welsh health Minister Vaughn Gething to highlight that people in Wales would be worse off under the new English scheme.
- July 2016: England only scheme announced for Infected Blood Support.
- 29<sup>th</sup> July 2016: Haemophilia Wales challenge Welsh Government to demand Wales specific consultation to ensure that affected people in Wales could voice their concerns.
- October 2016: Meeting with the Welsh Cabinet Secretary for Health Vaughn Gething: a 12 week consultation period agreed with the English scheme adopted as an interim measure.
- December 2016: Consultation and Workshops in North Wales.
- January 2017: Consultation and Workshops in South Wales.
- 25<sup>th</sup> January 2017: Welsh Government vote unanimously in favour of a UK wide Public Inquiry into Contaminated Blood.
- 30<sup>th</sup> March 2017: New Wales Infected Blood Support Scheme was established at Velindre in Cardiff in 2017.
- 17<sup>th</sup> May 2017: Haemophilia Wales and the Cross Party Group ensure that Welsh Labour gives a commitment to hold a Public Inquiry into contaminated Blood is included in Labour Manifesto.
- 21<sup>st</sup> June 2017: Truth and Justice Protest at the Department of Health: Haemophilia Wales, Welsh MPs and victims Letter delivered to number 10 by Bronwen Morgan demanding a

Public Inquiry. In Theresa May's opening speech Albert Owen Anglesey MP intervenes to ask for Public Inquiry.

- 11<sup>th</sup> July 2017: Public Inquiry into contaminated blood announced by Theresa May.
- 28<sup>th</sup> September 2017: Cross Party Group on Haemophilia and Contaminated Blood write to APPG to asking them to support Judge led Chair.
- Justice Brian Langstaff announced as chair of Public Inquiry January 2018.

#### **Draft Terms of Reference:**

#### Wales Specific Issues

- Address the Wales specific Issues resulting from involvement and response of the Welsh office following the advent of the UK's first confirmed HIV infected haemophiliac
- Investigate why the ratio of contamination of Haemophiliacs in Wales is higher than in the rest of the UK.
- Investigate why the death rate from Hepatitis C stage 1 and 2 is higher in Wales than in the rest of the UK
- The Inquiry should have core participants from Wales with Welsh legal representation.

- Welsh language considerations
- The role of the Welsh Office
- The role and responsibilities of the Secretary of State for Wales
- O The role of the Welsh Blood Transfusion Service
- O The role of the Chief Medical Officer for Wales

#### Full disclosure

- The Terms of reference should seek to establish the facts surrounding the contamination of the UK blood supply
- Ensure the full disclosure of documents across all government and clinical departments and from suppliers within the pharmaceutical and blood production sectors.
- Have the power to compel witnesses to attend the inquiry
- Address the unanswered questions with in the Penrose/Archer Inquiries and release previously redacted or undisclosed information
- Appoint a forensic accountant to review the accounts of companies involved in the supply of blood products to the NHS during the period covered by the Inquiry

- To cover all infections and pathogens associated with the disaster
- Establish accountability/responsibility across the range of interconnected disciplines and organisations
- Finally establish an accurate set of data regarding the scale of the tragedy. How many people have been infected, how many have died and how many affected family members remain.

#### **Blood supply**

- Examine why blood and blood products continued to be used after the point where reasonable risk to patients had been assessed
- To investigate the systems in place across the UK for the collection, treatment, licensing, testing, preparation of blood and blood products.

#### **Policy**

- Examine why patients were not fully informed of the treatment risks and why when infected there were attempts to restrict knowledge of the infection which could have prevented further contamination of family members
- The treatment of mild and moderate Haemophilia with concentrates and why alternative safer treatments weren't used.
- Self Sufficiency in Blood products: Why money allocated for self sufficiency was allocated elsewhere. Why the inaccurate Self

Sufficiency in Blood Products report written by the Department of Health in 2006 continued to be used as the defacto document to brief Ministers and MPs until it was withdrawn in 2017.

- When responsible bodies became aware of risks: why patients were not informed of the risks, why alternative treatments weren't used.
- Examine why the commercial interests of the Department of Health, the pharmaceutical companies and the UK Haemophilia Doctors Organisation (UKHCDO) took precedence over public safety.
- Examine the extent to which clinician's/policy makers/responsible bodies, decisions were compromised by marketing inducements or Non Executive appointments.

#### **General Considerations**

- The role of the Haemophilia Society in advising patients to continue to use treatment. The Haemophilia Society apologised for their role in the contaminated blood scandal on 28<sup>th</sup> March 2016, they cannot represent Welsh victims.
- The role of the Pharmaceutical companies
- The role of the Macfarlane Trust, Skipton Fund and Caxton Foundation

- To investigate whether the Secretary of State for Health entered into compromise agreements with HIV infected individuals who brought personal injuries claims without disclosure of known risks associated with Hepatitis C.
- Missing documentation, medical records, misconduct by responsible bodies and organisations. Data collection and why the Department of Health has not accurately recorded deaths from HIV and Hepatitis C.
- Why Lord Owen's departmental papers were destroyed by a 10 year rule which does not exist. Confirmed by Lord Prior to Baroness Featherstone April 2016.
- The relevance of Crown Immunity to the outcome of The Inquiry

#### The Aftermath

- o Recommendations on compensation with a time limit of 1 year.
- Support for the Infected (but not the affected) since 2017 has been provided by the Wales Infected Blood Support Scheme and financed by Welsh Government. All future recommendations on treatment will be financed by the Welsh Assembly Government and it is imperative that Wales and the devolved nations have input into these recommendations
- Assessment of the Impact on the Infected and affected
- Investigation of responsible bodies to include:

- Secretary of State for Health
- Secretary of State for Wales
- NHS Blood Transfusion Board
- Welsh Blood Transfusion Service
- Scottish National Blood Transfusion Service
- National Drugs Advisory Board
- UK Haemophilia Doctors Organisation (UKHCDO)
- UK Haemophilia Society
- Their employees, servants and or agents
- Lessons learned for the future.

#### Variant CJD:

- Why funds are not being made available for the development of a test for VCJD. A number of patients in Wales have received blood products from a blood donor who subsequently died from VCJD.
- Whether sufficient lessons have been learned as demonstrated by the handling of VCJD and the social and economic impact of the disaster on those affected.
- Future treatment recommendations will be the responsibility of Welsh Assembly Government and Wales and the devolved nations must have a voice in these recommendations.