

Witness Name: Katherine Victoria Burt

Statement No.: Fifth WITN6392288

Exhibits: WITN6392289 – WITN6392300

INFECTED BLOOD INQUIRY

WITN6392293

THS Presentation to IBCA
Clive Smith - Chair
Conan McIlwrath - Chair Elect
Debra Morgan – Inquiry Lead
Kate Burt - CEO

- 1 Severe Haemophilia A**
- 2 Chair of the Board of Trustees**
- 3 Chair of Public Inquiry Sub-Committee**
- 4 Chair of WFH Youth Committee**
- 5 Patient Representative**

UK Rare Disease Framework Board

- **Only UK - wide charity for people with inherited bleeding disorders**
- **Over 70 years old**
- **5, 000 + members – Patients, families, HCPs**
- **London Based – London Bridge**
- **Senior Management Team & Board (10 Staff – Mix of FT/PT, 1 Treasurer/9 Trustees)**

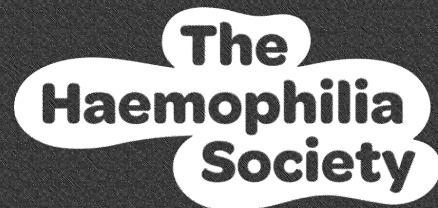
PATIENT ORGANISATION

- Finance & Risk Committee
- Public Inquiry Sub-Committee
- Women's Committee
- Youth Committee & Youth Ambassadors
- VWD Committee
- Rare Bleeding Disorders Committee
- Clinical Advisory Group

- **National Member Organisation for WFH & EHC**
- **Secretariat to APPG on Haemophilia & Contaminated Blood**
- **Run Newly Diagnosed Weekends**
- **Women with Bleeding Disorders – Talking Red**
- **The Big Get Together/AGM**
- **Youth Camp**

How are we funded?

- No government funding (£500,000 post Archer)
- Pharma & non pharma industry (grants and trusts)
- Community fundraising & legacies
- Report recommends funding for patient advocacy groups



Infected Blood Inquiry

Infected Blood Inquiry

Charity reg. no: 288260 in England & Wales SC039732 in Scotland

WITN6392293_0008

- 1** How we finally achieved an inquiry
- 2** Where are we now?
- 3** The final report & beyond

- Previous inquiries in the UK
- Archer Inquiry in 2008 – non-statutory
- Penrose Inquiry 2015 – Scotland only
- In July 2017 – Theresa May PM announced public inquiry
- Contaminated blood and blood products
- Full statutory inquiry

Pre-Inquiry announcement in 2017

- c. 5,000 infected
- Over 3,000 have now died
- 1,243 infected with HIV – just over 200 remain
- HIV litigation in 1990 – waiver signed by claimants
- Trusts and support schemes set up for HEP C
- Campaign for a public inquiry has never gone away
- Sadly, time has caused division

Why?

- Political climate at the time was very important
- Group Litigation Order – Challenging the HIV waiver
- Andy Burnham MP – last speech in Parliament
“evidence of a criminal cover-up on an industrial scale”
- General election – incumbent government did not have a majority
- Leaders of all opposition parties had signed a letter of support

Getting up and running

- **Appointing a Chair – Sir Brian Langstaff, retired High Court Judge**
- **Terms of Reference – Consulted with the community**
- **The Inquiry team**
- **Sat in devolved nations**
- **3 phases – Personal testimony, investigation phase (HTCs, regional transfusion centres, pharma, charities etc) & investigation into government**
- **“Investigating a cover-up” – Sir Brian Langstaff**

- **July 2018 – ToR published, and Inquiry formally begins**
- **Intermediary service – anonymous interviews and themes**
- **Feb 2019 – Expert groups**
- **April 2019 – First oral evidence received – Further £76m support**
- **Inquiry “book-ended” with personal testimony**
- **Start – individual evidence**
- **End – panels of witnesses with themes**
- **Prof Sir Stephen Powis – lead on response to Inquiry**

Themes within the inquiry

- Failure to become self-sufficient in production of FVIII
- Testing without knowledge and consent
- Failure to communicate test-results to patients
- Stigma of living with infections – Tombstone Campaign
- Devastating impact of interferon treatment
- Inadequacy & inconsistency of support schemes
- MFT & others – re-traumatisation of the community



The Haemophilia Society

- **Named within the Terms of Reference (ToR)**
- **Advice given in 1984 to continue with treatment**
- **Advice provided by Medical Advisory Group (MAP)**
- **Disclosed over 30,000 documents to the inquiry**
- **Waived Legal Professional Privilege**
- **Former staff and trustees gave evidence in February 2021**

In parallel to the Inquiry

- **Managed to improve financial support for those currently on infected blood support schemes**
- **Raised the issue of mental health – England left behind...(£19m)**
- **Compensation Study – happened in parallel**
- **Government maintained had to wait for full report**
- **Overnight, made an announcement on compensation**
- **Built bridges between campaign groups and charities**

The Inquiry Week – May 2024

- **Monday – Sir Brian published his final report**
- **However – the Inquiry is not yet closed**
- **Tuesday – Government announced its plans re compensation**
- **Wednesday – General Election called**
- **Thursday – Limbo**
- **Friday – Victims and Prisoners Bill passed into law**

- 1 Severe Haemophilia A**
- 2 Chair Elect to the board (November)**
- 3 Public Inquiry Sub-Committee**
- 4 Co-Chair of Friends and Families of Haemophilia NI**
- 5 Patient Representative NI Infected blood stakeholder group.**

What next?

- **Trusted Partnership**
- **The Critical friend**
- **Haemophilia Alliance**
- **The APPG**
- **Meet the community – Our events, webinars and meetings**

What next?

- Learn from the Inquiry's example
- Embrace the help that is out there
- Be transparent
- Accelerate the process and avoid mistakes of the past
- Our Services

We Need Each Others Help.

Questions