Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

# **INFECTED BLOOD INQUIRY**

# WITN6392106

#### Present:

 Roddy Morrison (chair); 2. Gareth Lewis (trustee of Haemophilia Society (HS) and chair of Haemophilia Wales) Hayden Lewis (Haemophilia Wales) GRO-A (trustee of HS and chair of Scottish Haemophilia Groups Forum) 4. (volunteer with HS and registrant of Macfarlane Trust) 5. GRO-A 6. GRO-A (Manor House group) **GRO-A** 7. (Manor House group) **GRO-A** 8. (chair of HS Highland group) 9. (Manor House group) **GRO-A** 10. GRO-A 11. Ann Hithersay (trustee of HS) GRO-A \_\_(trustee of HS and chair of Grampian group) 13. GRO-A (trustee of HS and chair of Bristol group) 14. Michael Colver 15. Liz Rizzutto (trustee) 16. Margaret Unwin (Chief Executive of HS) 17. Sue Rocks (PA to CEO of HS) **Apologies:** 

**GRO-A** GRO-A Carol Grayson! GRO-A and Sue Threakell

#### 1. Introductions

Each person introduced themselves and explained why they were attending the meeting.

## 2. Areas of the campaign:

Roddy Morrison handed out a draft agenda for the meeting and commented on the areas of the campaign.

GRO-A asked if aspects of the Skipton Fund could be included such as second payment qualification and the possible lowering of requirements. He also stressed the ongoing need for safer treatment.

suggested that the effectiveness of recombinant treatment against plasma treatment should be questioned. Following discussion it was suggested that a questionnaire be sent to members asking them to give their experiences with regard to recombinant treatment as compared to plasma treatment. It was agreed to ask the Society's health sub committee to formulate a questionnaire which would also be available on the Society's will supply the information he has on the current research in this area. website. GRO-A

# - Call for a public inquiry:

It was noted that Channel 4 were making a drama/documentary on the first five years of HIV infection which should be available in 2006. Questions would be asked in the programme about why the original blood files were lost or destroyed. There was also talk of a documentary specifically about haemophilia.

It was also noted that the film by Kelly Duda on the Arkansas blood scandal which was due for release on 8 November might possibly be bought by the BBC or Channel 5.

There was discussion on the various inquiries undertaken around the world and copies of a letter from Lord Jenkin stating that "..all the files relating to contaminated blood have been destroyed" was circulated.

### **LEGAL: Scottish case**

GRO-A explained the background to the Scottish legal case. The court action concerned four fatal cases where the deaths had resulted from hepatitis C infection. The action was seeking to establish that the State is obliged to hold an inquiry by virtue of Article 2 of the European Convention of Human Rights into the deaths. This obligation extends to deaths of individuals from the acts and omissions of the State Authorities in the field of health care so as to establish the cause of death of such individuals under the care and responsibility of health professionals and any liability on the part of such health professionals.

It was further explained that should the case fail an award of costs would be made against the individuals therefore a Fighting Fund had been established and the Society had agreed to pledge an amount to the fund.

GRO-A also informed the meeting that the Scottish Health Committee would be taking evidence in support of an inquiry next year. This evidence had been due to be given by the Society in May 2005 but had been refused due to a misunderstanding on the part of the Scottish Executive with regard to the legal case.

It was agreed to circulate the various letters from the solicitor handling the Scottish legal case.

Further discussion on legal matters concerned GRO-A s comment that anyone who had received a letter stating that they may have received vCJD contaminated blood products was essentially given a "perception of harm" and was therefore entitled to take legal action under the 1987 Consumers Act. He said that Manor House group were taking up this matter.

#### **PARLIAMENTARY: APPG**

It was noted that many questions had been asked of MPs over the years and many needed to be asked again but with more emphasis. It was suggested that a template letter be prepared and members be asked to send the letter to their MPs. Roddy Morrison said that in order to formulate a letter we needed to have sight of the information and documents that are being used as a basis for questions. It was suggested that there be a separate forum on the website specifically for the campaign where information could be shared. It was pointed out that some people did not have access to computers. It was also suggested that a book of the various letters be assembled.

It was agreed that a strategy needed to be devised and to this end the following was compiled:

# **CALL FOR AN INDEPENDANT PUBLIC INQUIRY**

Justice = an explanation; protection for the future; a place in history; compensation; an apology

Basis of call:

- Knowledge that files had been destroyed
- o The question of whether product licences were available at the time
- o Scotland no re-call of known contaminated products until 1991

#### **Evidence resources:**

- vidence resources:

  Use Irish experience = invite Raymond Bradley (solicitor) to this group and locate English
- Use Canadian experience = Krever Report
- "NHS caused illness" current issue = 980K last year made ill
- Charles Kennedy list = public exposed to 10 pathogens (BN)
- HTVL1 payout reference and driver
- Freedom of Information Act
- personal medical records (UKHCDO,NHS)
- HIV national significance = 20 yrs hereditary conditions lifetime
- Liverpool website (GL)
- · Lord Jenkin letters (AG)
- Discrepancy "infected" v "informed" 1984-1994 solicitor Norfolk (MC)
- Testing without consent
- Scottish documentary
- Charles Clarke letters asking for clarification of Freedom of Information Act and availability of files under 30 year rule dated January 2005 - reply received October 2005 but dated 7 March 2005
- Justice Ognall direction (HL) original settlement no-one was sent a copy of the report in
- Discrepancy between letter sent to AG and letter sent to MC (clarification required)
- Report to Crown Office from Chief Constable need a copy
- Equivalent papers in England and Wales of Scottish BTS directors' minutes
- Medical Inspector's report (Robert McKie)
- Consumer Protection Act = 3 people March 2002 judgement, assumed earlier infection cannot prove; products were in use (HL records show G1+ve 1st time??????; Haemophilia Society holds these
- US litigation = Criminal cases in Canada v pharmaceuticals, meeting /news imminent. If fails, may come back to UK for British people to sue through British courts. US cases have succeeded
- Scottish legal action Margaret Unwin to meet counsel 15 November 2005
- Scottish Parliament health committee receiving evidence early 2006
- Press resource Mark Weaving of Myriad taken on
- Lord Owen Review (internal review by instigated by Hazel Blears in 2002 into why UK did not become self sufficient following Lord Owen's directive) – due soon, supposedly completed and with printers
- Barrister's opinion )

# To question:

- Why there was no Secretary of State for Health from June 1975 to 1976
- Lord Morris' use of the word "inadvertent"
- Lords' use of the word "compensation" where there has been no compensation

# SKIPTON FUND - to demand

- Inclusion of widows and bereaved families
- Clear explanation and justification of the criteria for second payments
- Psychological effects/clearers be taken into account
- · The setting up of an Appeals system
- A revision of the cut off dates or no cut off dates

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# **RECOMBINANT** – to demand

- Efficacy
- Inquiry possible criminal action

### **ACTION:**

- -1 some Look into Crown Immunity HS
- Engage the support of the UKHCDO and release of information **HS**
- Copy notes to all campaign supporters on list and ask for any more ideas HS
- Put summary on the website **HS**
- Collate a library of evidence, documents etc GL/RO/HS
- Look into gaining a grant to fund a proper archivist to do a history project HS nd Uer
- Template letter HS and all A4 one side to individual MPs asking for inquiry referencing above points
- Respond to press articles of related interest HS new press officer taken on, Mark Weaving of Myriad PR
- Use of press releases / press association HS -
- Local press contacts All
- Signing letters HS (may be necessary for letter to be signed by CEO/Chair)
- Use APPG and Lord Morris HS
- Liberals Charles Kennedy (AG / BN) and GRO-A (GL)
- Ask UKHCDO for support/ advice/information
- Ask retired directors such as Eric Preston and others and for help
- Archive of pharmacy departments HL
- Direct action at each Parliament (Scotland, Wales, England and Northern Ireland)

## Key dates:

O World Haemophilia Day 17th April (EUS Harhanday)
O Date of possible Arkansas documentary broadcast

Carper of lillies?

Next meeting in January 2006.

Health Adot (amouther

& Individuals write to the Parliamentary

\* write to charles Kennedy.

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