

Minutes taken by Ollie Carruthers  
as Carl doesn't minute such meetings!

Minutes of meeting at NHS London 15 May 2002

Start time 16.30

In attendance

NHS

Yvette Cooper... Public Health Minister

Charles Lister... Head Civil Servant (haemophilia and blood)

Two others not introduced

Manor House Group

D Tonkin Chair

GRO-A

Co-chair

GRO-A

Organiser

Haemophilia Action UK

Carol Grayson Founder

Ollie Carruthers

Members of Parliament

Sylvia Heal MP (Halesowen)

Paul Goggins MP

Unable to attend

Fraser Kemp MP

Jim Cousins MP

Sylvia Heal opened the meeting by mentioning the poor quality of life suffered by those with hepatitis C. Then introduced Dave Tonkin and request he introduce the other members of the Manor House Group and Haemophilia Action UK.

D Tonkin 'Introduced all including The MPs. Mentioning that the two groups were bringing evidence, showing alleged negligence and a lack of ethics by the NHS. He introduced the agenda;

- 1) Self-sufficiency (UK blood products).
- 2) The Lord David Owen issues.
- 3) Patients right to be informed of risk of treatment.
- 4) The moral issues.
- 5) Ignored warnings.
- 6) Public inquiry.
- 7) No fault compensation.
- 8) Stigma surrounding haemophilia and hepatitis c.'

He requested Peter Mossman to start with self-sufficiency.

Self-sufficiency.

GRO-A

' Stated he had no reply from a letter, to the NHS, dated 25 February 2002, he therefore quoted from a reply, dated 24 April 2002, sent to his MP Peter Goggins. The letter had stated the reason there had not been self-sufficiency in British blood products was the steep rise in demand. This he disputed stating the real reason was lack of investment in BPL during the 1970 - 1980s. Producing documents from the health inspectorate (NHS documents) stating that BPL would have been condemned outright if it had been a private company. Quoting particular instances of neglect such as fungus on the very products used on haemophiliacs. It was also stated that during follow up visits no significant improvements had taken place. This led to import of (known) infected products. Stated that deaths from hepatitis C had risen in the past year from to 250.' Carol Grayson 'Stated many deaths had previously been attributed to HIV therefore this figure was an underestimate.'

**OLLIES NOTE; I HAVE A DATE OF 31 JULY 1981 REFERING TO IMPORTED PRODUCTS, CAN ANYONE TELL ME ITS SIGNIFICANCE?**

D Tonkin ' The company had to reduce production because of 'deplorable conditions, if private it would have been closed, this was reason for shortage.'

Carol Grayson 'BPL did not reach even minimum safety standards.'

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**GRO-A** 'BPL were known to hire and use untrained staff'

Lord David Owen issues.

Yvette Cooper 'There had been an initial investigation, which showed that the money promised, by Lord nee Doctor David Owen, had been used correctly'. No documents produced.'

Carol Grayson 'Dr David Owen promised self sufficiency on the grounds of safety no matter what the cost, not fulfilled', went on to mention 'United States cases being won by lawyers who had said they would finance an action here, based on the prison blood scandal etc asking Yvette if during her time with the Clinton campaign in Arkansas in 1992, as domestic policy advisor, she had met Leonard Dunn, Clinton's campaign advisor. Yvette Cooper denied any knowledge of Leonard Dunn. Suggested that Yvette might like to use her old contacts in Arkansas to check out prison blood info.

Patients' right to have been informed of the risk of treatment (informed decision)

**GRO-A** 'Garret Allen, top hepatitis expert in the US, asked HM Government not to use U S blood products as deaths had been attributed to hepatitis (non A non B, now hepatitis C) Documented 6 January 1975.' D Tonkin 'If heat treat had been introduced earlier then 70% or more of infections would not have occurred.' Carol Grayson 'This could have been researched years earlier when it was discovered that heat treatment killed the hepatitis virus, but as this was costly because of yield loss it was decided to use the haemophilia community as guinea pigs. The treatment prior to concentrates was a relatively safe treatment called Cryoprecipitate. What were the ethical guidelines on factor concentrates, as they were introduced without informing the patients and no testing had taken place?'

D Tonkin 'Haemophiliacs not told of change of treatment,, no warnings no choice, no patients rights.' Carol Grayson 'Low incidence of hepatitis in cryoprecipitate, but changed to pools of thousands -up to 20,000.. Baxter and other plasma companies advertised in Gay magazines for blood to use in treatment of hepatitis (vaccines) from infected donors, but as they collected more than they needed it was put into the general pool, for factor VIII, knowing it was contaminated.' Carol Grayson produced the documents. 'Prisoners gave blood under false names sometimes days before being hospitalised and often dying of hepatitis' Photographs and documents produced. Ref to L Miller.

**GRO-A** 'Read out ethical position in the U S where Professor Christine Lea stated policy of mid 80s was not to discuss with patients.' Was this the stated policy here? Why?

Moral issue

D Tonkin 'Stated "we have no confidence in the Haemophilia Society'.

Carol Grayson Pointed to "the conflict of interest due to funding from the very organisations that caused the viral problems and the NHS.'

D Tonkin 'Why is there discrimination of Haemophiliacs regarding proof. Stating other cases had been given no fault compensation. Why has the government turned its back on this community. There has been no financial help and stated policy is no blame no claim.'

**GRO-A** 'Had to move houses twice due to vandalism, because of his hepatitis illness.'

D Tonkin 'I have faced four ministers and we are not going away, until we have justice'.

**GRO-A** 'Showed pictures of a Manor House Group member dying due to Hepatitis C, showing an ill bloated body in a hospital bed.'

Carol Grayson 'Public inquiry is required as HIV payments forced people to sign a waiver for hepatitis virus. Dr Galbraith Public health said in 1983 all products made in U S from blood collected before 1978 should be withdrawn, this was not done'.

D Tonkin '1989 consumer protection act paid out but not to hep C pos haemophiliacs, is this fair?' Why is the government prepared to give safe treatment to children but not adults, in the form of Recombinant a synthetic product proven safer.'

Carol Grayson 'We can not work with Haemophilia Society who promotes the use of paid donors; this has led to thousands being infected in China due to collecting method, shared equipment. EU has asked for no paid donors on grounds of safety the Haemophilia Society is actively campaigning for this to be changed for British Haemophiliacs to be exempted'

Reply from Yvette Cooper

The increase in need for plasma products was the reason for importing concentrates. She was in contact with David Owen checking why papers were pulped. She would check BPL inspectorate records 1976 -80.