Witness Name: GRO-B Statement No: WITN0670011 Exhibits: WITN0670012-13 Dated: 22.11.2019 INFECTED BLOOD INQUIRY WRITTEN STATEMENT OF I provide this further supplementary statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5 March 2019. GRO-B will say as follows: -Section 1. Introduction 1952. My 1. My name is GRO-B My date of birth is GRO-B GRO-B address is 2. I wish to make the following additions to my statement concerning EIBSS and a response I received from them in connection with a Freedom of Information request (FOI) I submitted. 3. I make this second supplementary statement in addition to my statement of 31 July 2019.

#### Section 2. Other Issues

- 4. I am making a further supplementary statement to the Inquiry because I have received a reply to a Freedom of Information request I made to the English Infected Blood Support Scheme (EIBSS) that I find to be extremely alarming and unsettling.
- The English Infected Blood Support Scheme refused my application for Stage 1 Payments on GRO-B 2019 on the 'balance of probability' that I was not infected with HCV by a blood transfusion.
- 6. Evidence based medicine and clinical decisions rest largely on epidemiological studies and statistical associations and as such any 'balance of probability' should be calculated using data, peer reviewed epidemiological studies and statistical modelling. I made a Freedom of Information request to the EIBSS on GRO-B 2019 which asked, 'what data does the English Infected Blood Support Scheme use to calculate its "Balance of Probability" test? What statistical model is used to calculate the "Probability"?'
- 7. The reply from EIBSS that I received on GRO-B stated, 'the English Infected Blood Support Scheme (EIBSS) will examine all available information and evidence provided by an applicant, and it is this information and evidence that is used to determine the balance of probability. To calculate probability, EIBSS needs to establish whether a case is more likely than not. This means that a conclusion would need to be reached that it is more than 50% likely or above, that certain events took place in order for that case to be proven on the "balance of probabilities".'
- So, when the EIBSS make an evidence based 'balance of probability'
  decision, it follows that, if evidence based clinical decisions are made
  using epidemiological data and statistical associations, then the EIBSS

need to disclose which data and statistical evidence they use to make a 'balance of probability' decision.

- 9. The EIBSS are obliged by law to answer my FOI request correctly and I felt they were being evasive and deceitful with their reply because they did not reveal what studies, data and statistics they use to make their 'balance of probability' decisions. As I stated in paragraph 3, epidemiological studies, data and statistics are used to calculate probabilities. In determining a 'balance of probability' decision on an application for assistance, the EIBSS should apply models, derived from epidemiological statistics of a population, to a single case. It follows that any inferred reasoning used to determine a 'balance of probability' is derived from those statistics. That is what I asked in my FOI request as well as asking what statistical modelling was used to arrive at a 'balance of probability' decision. It is clear that the EIBSS do not wish to disclose which epidemiological data and studies they use to determine a 'balance of probability' decision, for some reason best known to themselves. I suspect it is because the practise is problematical and may be easily challenged.
- 10. They state that they, 'examine all available information and evidence provided by an applicant', but do not state the relevant data and epidemiological studies from other sources that would be available to them to determine the 'balance of probabilities'. Because the evidence of the applicant for assistance does not stand on its own then surely it must be examined and considered against a similar set of circumstances in order to arrive at the 'balance of probability'?
- 11. The EIBSS state, 'a conclusion would need to be reached that it is more than 50% likely or above, that certain events took place in order for that case to be proven on the "balance of probabilities",' but make no mention of how they are measuring the 50% on which their decision is based, i.e. 50% of what? If the EIBSS are making decisions about infections contracted through NHS blood or blood products before 1991

then, as a matter of course, they would have to interrogate historic epidemiological studies, data and statistics associated with them in order to arrive at those decisions.

- GRO-B 2019 as I was not satisfied with their reply to my earlier request of GRO-B I received a reply from them on GRO-B and it seems their practice of determining a 'balance of probability' is for Medical Assessors to, 'use their experience and judgement in determining the credibility of each piece of evidence and how much weight to assign to each piece of evidence. The resulting decision will be that it is more than 50% likely or above, that certain events took place in order for that case to be proven on the balance of probabilities'. How do they assign 'weight' to any piece of evidence and how do they apportion that weight, i.e. what techniques do they use? Are they statistical? Are they mathematical? Again, no mention of any recourse to epidemiological evidence, data or statistical associations is made.
- 13. This then begs the question of, who are these 'Medical Assessors', what are their qualifications and what information (data, statistics) are they using to make that 'balance of probability' decision? Are they medically qualified or have they received medical training? Do they read and assimilate all the current papers and studies regarding contaminated blood and the vectors of transmission in the ever-changing world of HCV, haemophilia, HIV, vCJD and other associated infections and conditions so that they can make fair and unbiased decisions in line with contemporary thinking and knowledge?
- 14. If a decision cannot be interrogated by others using available and reliable data/information/studies/research papers, then the 'balance of probability' decision, if not supported by evidence, is solely one of 'opinion' and is a blatant disregard of the responsibilities of the Scheme. It fails to address its remit to be fair and transparent and meet the commitment from the Department of Health to the people who were

infected by contaminated blood. This is neither an equitable nor scientific evaluation of an application for Stage 1 Payments or any other financial assistance by the EIBSS nor is it, I suspect, defendable in a court of law.

- 15. Finally, I have read that the English Infected Blood Support Scheme was set up to create a more accessible and equitable system of care and support that focussed on the welfare of infected individuals. It was to be fair and transparent and the Department of Health was committed to ensuring that all those infected and affected would be supported. Why is it then that the EIBSS is evasive, disingenuous, duplicitous, resistant to imparting information and extremely indifferent to people's circumstances and feelings? They should be helping infected and affected people, as is their remit, not hindering them.
- 16. I have made both FOI responses available to the Inquiry. (WITN0670012; WITN0670013)

#### Statement of Truth

I believe	e that the facts stated	in this witness statement are true
	GRO-B	
Signed		

Dated 20/1 /2019

## **Exhibits**

Exhibit No.	Description	Date	
WITN0670012	Email response from EIBSS to witness	GRO-B	
WITN0670013	Further email response from EIBSS to witness	GRO-B	