Witness Name: Dr John Collinge
Statement No.: WITN3093001
Exhibits: NIL
Dated: 16 May 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JOHN COLLINGE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 25 April 2019.

I, Dr John Collinge, will say as follows: -

Section 1: Introduction

1. My name is Professor John Collinge and my address is MRC Prion Unit and Institute of Prion Diseases at UCL, Courtauld Building, 33 Cleveland Street, London W1W 7FF. My date of birth is GRO-C 1958. My professional qualifications are BSc, MB ChB, MD, DSc (Hon), FRCP, FRCPath, FMedSci, FRS.

2. I qualified in Medicine from the University of Bristol in 1984 and underwent postgraduate training in medicine and neurology before being appointed an Honorary Consultant in Neurology at St. Mary's Hospital in London in 1994 where I was also a Wellcome Trust Senior Fellow in the Clinical Sciences and from 1996 a Wellcome Trust Principal Fellow in the Clinical Sciences at the Imperial College School of Medicine. I established a specialist NHS clinic for prion disease at St Mary's Hospital which was later designated the NHS National Prion Clinic. In 1998 I founded and established the Medical Research Council (MRC) Prion Unit at Imperial College School of Medicine at St Mary's with a national strategic role in prion research. I relocated, together with the MRC Unit and NHS National Prion Clinic, to the UCL Institute of Neurology and National Hospital for Neurology and Neurology (part of UCLH NHS Foundation Trust) at Queen Square London in 2001. I was appointed to an established chair in neurology at UCL in 2001 and founded and headed a new University Department of Neurodegenerative Disease. In 2017, the MRC Unit, in line

with MRC policy, became a part of UCL and was renamed the MRC Prion Unit at UCL. As part of this change I left the Institute of Neurology to establish a new UCL Institute of Prion Disease within which the MRC Prion Unit at UCL now sits. My current appointments are as Professor of Neurology at University College London (UCL), Honorary Consultant Neurologist and Director of the NHS National Prion Clinic at the National Hospital for Neurology and Neurosurgery UCLH NHS Foundation Trust, and Director of the MRC Prion Unit and Institute of Prion Diseases at UCL. In 2017 I was appointed visiting Professor of Neurology at Harvard Medical School, USA.

3. I served as a member of the UK Government Spongiform Encephalopathy Advisory Committee (SEAC) from 1996-2002 and from 2007-2010. I also served a member of the Department of Health (DoH) /MRC Steering Group for Studies of Detectable PrPSc, the DoH CJD Tissue Management Steering Group (2002 – 2007), the DoH CJD Therapy Group (2002 – 2004) and the MRC New Therapies Scrutiny Group (2005). I served as Deputy Chair of the European Union High-level group on Bovine Spongiform Encephalopathy (BSE), (1996) and was a member of the TSE group, Scientific Steering Committee of the European Union (2001 – 2003). I have also served on various World Health Organisation (WHO) groups on transmissible spongiform encephalopathies (prion disease). I am a member of the CJD International Support Alliance (CJDISA) Friends and Advisors Group.

Section 2: Response to criticism of Peter Buckland

4. Firstly, I would like to express my sympathies to Mr Peter Buckland for the suffering and loss he and other members of his family have endured and continue to endure following the illness and death of his son from iatrogenic (blood transfusion-associated) variant Creutzfeldt-Jakob disease (vCJD). It was a privilege to be involved in the care of his son and I found his testimony very moving.

5. All prion diseases, including vCJD, are invariably fatal degenerative conditions of the brain and there are as yet no treatments which alter the course of the disease. A key part of the mission of the MRC Prion Unit since its inception has been the development of disease-modifying treatments. Following a published report from scientists in the USA in 2001 suggesting, based on their laboratory studies, that the drug quinacrine may have therapeutic benefit in CJD, the MRC were asked by the Chief Medical Officer to establish a formal regulated clinical trial to investigate

whether quinacrine might offer benefit to patients with prion disease. This led to the PRION-1 trial, which was funded and sponsored by the MRC and involved both the MRC Prion Unit and the MRC Clinical Trials Unit. The trial was approved by the Eastern Multicentre Research Ethics Committee and overseen by a Trial Steering Committee and a Data and Safety Monitoring Committee. The trial recruited 107 patients with prion disease and the results were published in the peer reviewed journal *Lancet Neurology* in 2009. Unfortunately, while the drug was reasonably tolerated by patients, we found no evidence that it affected the clinical course of prion disease.

6. Quinacrine is a drug that had been extensively used in the past for treatment of malaria and also rheumatoid arthritis. While oral use was considered safe, quinacrine as with all drugs had known side effects which were explained as part of the consent process. These included a lemon discolouration of the skin (quinacrine is a bright yellow substance and can deposit in the skin) and a risk of damage to the liver. The yellow discolouration of the skin is harmless and reversible and all patients on quinacrine had close medical supervision and regular blood tests to detect early signs of liver toxicity. Drug dosage was reduced accordingly if blood tests of liver function were abnormal so as to prevent any serious or irreversible damage.

7. The Inquiry has interpreted paragraph 39 of Mr Buckland's statement as professional criticism of myself and asked me to respond accordingly. However, with respect, the statement on which I am asked to comment: "Professor Collinge and his team were trying to cure Mark by using a drug but all it did was to affect his liver and make him slightly yellow" appears to me to be a statement of fact rather than a professional criticism. I only wish we could have done more but unfortunately there remains no known effective treatment for this dreadful disease; we continue to work to develop one.

Section 3: Other Issues

8. I am assisting the Inquiry team with their earlier rule 9 requests for provision of documents from the MRC Prion Unit and UCLH NHS Foundation Trust relevant to the Inquiry's investigation.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-C

Dated 17/5/19