Witness Name: Gillian Turner
Statement No: WITN5254001
Exhibits: none
Dated: 12 April 2021

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GILLIAN TURNER MBE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13th October 2020. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Gillian Turner, will say as follows:

Section 1 Introduction

1) Please state your name, address and date of birth.

1. My name is Gillian Turner and my address and date of birth are known to the Inquiry.I make this statement to describe my involvement as National Co-ordinator for the UK CJD Support Network (CJDSN) from December 1996 to my retirement in September 2020, insofar as it is relevant to the Inquiry's Terms of Reference.

Section 2: Organisations involved in campaigning activities

2) Describe your involvement in setting up:

a. any campaigning organisations whose aims or activities are relevant to the Inquiry's Terms of Reference; and/or
b. any organisations offering support and assistance to people who are infected or affected.

State when each organisation was set up, what prompted or led to its establishment and what its aims and objectives were or are.

3) Identify any positions you held within the organisation, the dates that youheld these positions and your role and responsibilities in that capacity.

4) Describe the main activities of the organisation, and any outcomesachieved by the organisation, over the years since its establishment.

CJD Support Network

2. The CJD Support Network was established in 1995 by relatives of people who died with CJD and is now recognised as the leading charity for all forms of CJD.

3. The Network officially started in 1995 as part of the Alzheimer's Disease Society. The Alzheimer's Society were supporting all the dementias at that time and receiving enquiries from people who had lost loved ones to CJD. CJD was a rare dementia, and many health workers had never seen a case. Very little information about the disease was available in written form for health professionals/social work professionals and/or lay people. This suddenly changed when the first cases ofvariant CJD were discovered. Consequently, the Society decided to apply to the Department of Health for funding for a small support group specifically for CJD.The Society were allowed the funding, which enabled them to advertise for a National Co-ordinator. This was at the start of vCJD in 1994 before it became a 'high profile' disease. I applied for the position and was appointed the National Co-ordinator for the CJDSN on the 2nd December 1996. However, I recently made the decision to retire and I terminated my employment with the CJDSN in September 2020.

4. When funding was withdrawn by the Department of Health in 2003, the Alzheimers Charity said they could not accommodate the CJDSN as it was taking too much of their resources. The CJDSN fought for independent charity status and became registered as an independent charity within the year, (registered number 1097173). All assets from CJDSN were transferred to the new charity. We had a small team led by Dr Angus Kennedy as Chairman, Anita Tipping (Trustee) as Secretary, Mike Curtis (Trustee) as Treasurer, Maria Byrne (Trustee), John Gilbert (Trustee) and me, Gillian Turner, as National Co-ordinator. The Charity was registered at my home. Our aims were to promote and provide accessible, plainly written CJD information, advice, emotional and practical support, 24 hours a day, for children/young people, elderly/old people, people with disabilities, also carers, professionals and those at risk through secondary transmission. We aimed to promote good quality care, support, and interagency co-operation.

5. Initially, my role was to initiate a supportive group for families affected by all types of CJD, vCJD, Sporadic, Genetic and Latrogenic. CJD was a very rare disease. We created support for patients and their families affected by all types of CJD in the UK and ensured that patients and families were at the centre of any decisions concerning CJD. It soon became clear that this information was greatly needed, particularly when vCJD was discovered, as families and professionals alike were asking the same types of questions all over the UK and sometimes from abroad.

6. At that stage, this need, in addition to patient and family support, was determined as: information about CJD; awareness raising amongst professionals; guidelines for professionals; ensuring that patients and families were at the centre of planning; consistent care and peer support.

7. I received many calls from Social and Hospital workers. They were desperate for information on the new variant of CJD (vCJD). We were aware of the need to get information 'out there' for others to follow. The cases were continuing to increase and there wasno Government template in place for health professionals to work from (not unlike the present Covid 19 pandemic). Health professionals were worried as they did not know how to deal with this sudden outbreak. Many doctors, andeven hospitals, had never seen such cases before. Hospitals were not suitablefor patients with CJD symptoms and there was a shortage of Nursing Homes equipped for the age range (average age was 29). There was no Governmentguidance in place for health or social care to follow. I think there was

a lot of pressure and anxiety felt at that time by myself and my colleagues as we dealt with the chaos generated by the new variant, the pressure was also compounded by the amount of publicity it had generated.

8. When people called the CJD helpline, they would speak directly to me. I gave them the opportunity to discuss their concerns, worries and any other problems in relation to CJD and offered empathy, advice, and practical help. If they were having specific problems, I would assist them by speaking to the person/organisation that could help with the issue. I helped develop the Network by establishing annual family meetings, a regular newsletter, the CJDSN website and provision of care grants for families. I contributed to international events and collaborations in my role as National Co-ordinator and regularly attended andsat on several Government, Health and Social Care advisory committees.

9. The CJDSN was asked by America, Germany and Japan to help them to set up CJD support groups in their countries and many countries asked for permission to use our information and copies of our leaflets etc. to enable them to translate the information into their language.

10. The aims and objectives of the Network were to offer practical and emotional support to individuals and families concerned with all forms of CJD.We also offered practical and emotional support to people who had been told they are at a heightened risk of CJD through blood and surgical instruments.We provided emotional support for carers and linked families with similar experiences of all forms of CJD; offered financial support for families in need through CJD, provided accurate, unbiased and up to-date information and advice about all forms of CJD, promoted good quality care for people with CJD, promoted research into CJD and the dissemination of research findings, and represented the interest of individuals, affected directly or indirectly, in discussion with Government and public agencies.

11. My job also included completing complicated funding applications for further funding from the Department of Health on behalf of CJDSN. These were successful up to the final tranche in 2003, but then the Department of Health structures changed and our application for further funding was rejected, so we became totally reliant on public donations.

12. In 1997 I arranged the first CJD Support Network conference at Warwick University with help from colleagues at the National Alzheimer's Society. It

attracted over 300 delegates, 39 film crews and journalists from around the world. This helped raise the profile of the Network and CJD quickly became recognised in many other countries.

13. Also, in 1997, I planned and registered the first CJD Day with the agreement of the Alzheimer's Society. On 12th November 1997 I organised a candle-lit service held at St. Martins in the Field, in Trafalgar Square, London with a large attendance of affected families. As the event had been so successful, CJD Day was taken up by many other countries and is now an internationally recognised event on 12th November each year.

14. In March of 1999, I was invited to attend an international conference at the World Health Organisation (WHO) in Geneva. The conference examined the worldwide exposure to CJD, the prevalence and infection of CJD and the decontamination of medical instruments, nursing care, diagnosis, research andethical issues.

15. In October 2001 I attended at a function at the House of Lords as a guest of the Life Neurological Research Trust in memory of Baroness Wharton who died from CJD. The Trust raised money for further research into CJD and donated its first year's funds to the CJDSN.

16. In October 2001 I visited Japan on behalf of the CJDSN. I was invited to accompany a Japanese Solicitor representing Japanese families who were suing the Government for medical negligence, after many cases of human dura mater transplantation caused the onset of fatal brain disorder. The families won their case in Court on 14 November 2001. The State and two pharmaceutical companies were deemed responsible for the spread of brain wasting CJD in Japan. The case involved 28 victims. On that trip, I made many presentations in Tokyo, Kobe and Osaka and helped set up a Japanese Support Network. LaterI acted as host, in my home, to the Professor and his colleagues from the general assembly of the Japan CJD Network when they visited the UK.

17. On 31 December 2002 I was honoured to be awarded an MBE by the Queen in her New Year Honour's List for services to the work of the CJD Support Network and I received my award from the Queen at Buckingham Palace. The award was recorded in the London Gazette on 31 December 2002 (Edition 56797).

18. In 2003, on International Awareness Day, I arranged a special event in Liverpool where hundreds of balloons were released in memory of people who had died of CJD over the last 10 years: 502 yellow balloons in memory of those who died

from sporadic CJD, 34 green balloons in memory of those with iatrogenic CJD, 50 white balloons for those with familial CJD and 117 red balloons for those with vCJD.

19. During the years 2004 to 2011, I was invited to speak at many conferences around the World. These included those in: Washington USA, organised by the American CJD Foundation; conferences in Japan, Sendai, Tokyo and Kobe;in Milan to speak at the International Annual Prion06 conference; in Madrid to attend the Prion08 conference; in Brussels in 2011 to attend the EU conference on genetic treatments for brain diseases; and many of the annual CJD support Network Family Support Meetings.

20. In 2005 I attended a blood seminar on the 'Effectiveness of the safety of Blood' in place of Harry Cayton, Executive of the Alzheimer's Society, as he was unable to attend. The seminar was entitled 'Have we Lost the Plot'. At the meeting, I spoke about patients' expectations and the general concern about lack of internal communication and mixed messages between health professionals concerning the risk of CJD through blood transfusions.

21. When news broke out in July 2005 that possibly 100 blood donors were carrying the vCJD agent, there was a high influx of calls to the helpline. People were very anxious and worried. The volume of telephone calls to the helpline steadily increased over the following months and by 2011, the CJDSN was receiving an increased number of calls and supporting families with information and emotional support. By the time of my retirement in September of 2020, calls to the helpline regarding blood transmission had greatly reduced.

22. Through the helpline, I got to hear from individuals experiencing considerable problems in obtaining insurance cover and mortgages. I recall one such telephone call from an Estate Agent in Ireland trying to get a mortgage for a client. He had been informed by the insurance company that they would not consider offering insurance/mortgage for someone connected with CJD. It was not until we and others made many complaints to the Department of Health, that a meeting waseventually held with the insurance industry hierarchy, and around 2012, this policy was changed.

23. In 2011, Professor Richard Knight succeeded Dr Angus Kennedy as Chair of the CJDSN Charity.

24. In March 2012, due to the reduction in public donations to the CJDSN, my

employment was terminated. However, I was re-engaged as a freelance Consultant.

Section 3: Involvement in committees and/or working groups

5) **Set out your membership, past or present, of any committees or working groups relevant to the Inquiry's Terms of Reference.**

6) **Identify any positions you have held within any relevant committee or working group, the dates that you held these positions and your role and responsibilities in that capacity.**

7) **Describe what you can recall about any matters relevant to the Inquiry's Terms of Reference that were considered by the committee or working group of which you were a member, including your recollection of the information considered by the committee or working group, the discussions held and the decisions reached.**

I was invited to be a committee member on the following Government committees but unfortunately I cannot remember all the dates I served on them:

Department of Health (DoH)

25. In 1998, in response to a CJD Support Network survey that identified a lack of awareness, knowledge and understanding of the condition amongst social workers, I assisted Derek A. Biggs, Operations Manager at Cambridgeshire Social Services, who prepared the first set of 'good practiceguidelines' for Social Services professionals working with people with CJD. These were published in conjunction with the CJD Support Network and The Association of Directors of Social Services.

World Health Organisation

26. During my time with the CJDSN I have served on many Government Committees related to CJD. The purpose of this was to ensure that the needs of patients and families were always at the centre of every decision made by these groups.

27. As mentioned previously in my statement, in March of 1999, I was invited to a conference at the World Health Organisation (WHO) in Geneva and became part of a working group who developed worldwide protocol and precautions needed to prevent iatrogenic and nosocomial exposure to transmissible spongiform encephalopathies (TSEs) in hospitals, healthcare facilities and laboratories. The guidelines respond to the unusual Iresistance of TSE agents to conventional chemical and physical methods ofdecontamination and the corresponding need for special precautions. In issuing the guidelines, WHO aimed to help medical officers, specialists in infection control, care givers and laboratory workers reduce the risks of TSE transmission to negligible levels. The guidelines provide a logical framework for determining levels of risk and knowing when departures from standard procedures for infection control are required. Specific recommendations areset out in the guidelines, which ensure a high level of safety. The guidelinesemphasize that no TSE patient should be denied admission to a health facility, kept in isolation, or deprived of any procedure.

National Institute of Clinical Research (NICR)

28. The NICR is a physician owned and managed independent clinical trial management organisation, specialising in clinical trial management. The NICR is able to undertake multiple levels of research and planning necessaryfor any types of clinical trial, using the latest technologies enabling them to provide high quality clinical trials.

29. NICR's Clinical Trial Consulting division is an innovative, international drug and device development organization that delivers the full spectrum in consulting. It focuses on immunology and helping life-changing therapies success in chronically and critically ill patient populations. Its therapeutic approach provides pharmaceutical, biotechnology, and an expertise in clinical trials comprising of a unique mix of specialists from the following fields: academic, medical industry, nephrology, endocrinology, haematology,and cardiology.

30. At the end of 1998, we identified and submitted a proposal to the DoH for a Case co-ordination Project and obtained funding for three years from April 1999. Then in October 2000, following the BSE Inquiry Report, the Government announced a package of measures for people suffering from CJD and their families. The compensation package was meant for individuals with vCJD only,

but the CJDSN put forward the recommendation with others that those with any form of CJD and prion disease should benefit from the package. The DoH decided to follow the example of the CJDSN and they set up their own project at the National CJD Research and Surveillance Unit in Edinburgh. They were able to employ two specialist nurses and a research doctor to check any possible connection between cases. The CJDSN played an important role in helping the DoH to ensure the care fund was effective. £1 million was granted by the Government. This enabled an effective case co-ordination between health professionals and families. Two Centres of Excellence were set up, one in Edinburgh and the other at the National Prion Clinic in London and guidelines were prepared.

31. The extra funding meant that young people who would have possibly been placed in an unsuitable Nursing Homes with the lack of appropriate equipment, could now access or buy anything they were assessed as needing e.g. specialist chairs and other equipment and alterations to their home.

32. In 2000, the Department of Health published 'Guidance on CJD for Health Workers' to complement the guidelines for social workers of 1998. The Social Services Guidelines were subsequently amended and re-published in 2003. The guidelines were also re-published again for Health Workers in 2005/2006. We ensured the up-to-date guidelines were always available on the CJDSN website.

33. I recall in January 2001, the Government trying to trace haemophiliacs after the NHS admitted treating patients with a clotting agent made from a blood donor who later learned that he had vCJD. I remember the CJDSN receiving calls through its helpline from concerned members.

34. In 2008 I attended a meeting of the National Institute of Clinical Research (NICR) where discussion involved the preparation of guidelines and the care of patients.

Creutzfeldt-Jakob Disease Advisory Sub-Committee

35. I joined as a member of this sub-committee in September 2017. I contributed to the production of an Interventional Procedures Guidance for the National Institute for Health and Care Excellence (NICE), which was published on 22nd January 2020. The guidance is the interventional procedures on tissues

considered at high risk of transmitting CJD. These procedures are intradural surgery on the brain and spinal cord, neuro-endoscopy and surgery on the retina or optic nerve. The guidance sets out recommendations for decontamination of surgical instruments, surgical instrument tracking, supplementary instruments, neuro-endoscopes, single use instruments, systems specific to people born after 1996, and other relevant guidance.

National Institute for Health Research (NIHR)

36. I worked with NIHR on Improving outcomes in the third sector in the health and social care sector across the UK December 2018- 2019.

Scottish Health Department

37. In early 2001 I was part of a working group that helped prepare guidance for the Scottish Health Department. The guidance was to be actioned by Chief Executives of NHS Trusts and General Managers of Health Boards. It was to help healthcare professionals respond to the challenging care needs of patients suffering from any type of CJD, emphasising the importance of appointing key workers to ensure the co-ordination of services; the speed with which patients can deteriorate and the need to review care requirements constantly, also the appropriate precautions to minimise risks to carers in the home and hospital settings. The CJDSN worked closely with the National CJD Research and Surveillance Unit (NCJDRSU). When the National CJD Surveillance Unit (NCJDSU) became part of Edinburgh University it was renamed, the National CJD Research and Surveillance Unit.

38. I attended the first conference of a patient with CJD and assisted by providing information on effective forms of support, encouraging co-ordination and partnership between services and applying a unique understanding of carers' needs. I provided detailed advice to local agencies on the likely progression of the disease and the range of care services that may need to be put in place.

CJD Incidence Panel

39. I was a member of the CJD Incidence Panel between 2001 – 2013.

40. When attending meetings of the CJD Incidence Panel, often Committees from other organisations within the Department of Health would be invited to attend and we would all work together. I refer to my connection with the other Committees within my witness statement.

41. The Panel was established in 2000 on behalf of the UK Chief Medical Officer in order to advise all those bodies responsible for the provision and delivery of health care on how to manage incidents involving potential transmission of CJD between patients. The Panel was wound up March 2013.

42. The CJD Incidents Panel was made up of approximately forty professional individuals, advising hospitals, trusts and public health teams throughout the UK on how to manage incidents involving possible transmission of CJD between patients. It provided national advice and support to prevent the potential spread of CJD in a healthcare setting and provides advice to local trusts, health boards and health protection teams on the implementation of the CJD incidents guidance. It coordinates studies of the prevalence of abnormal prion protein.

43. In 2001 the CJDSN were asked for a representative to sit on the Panel and I was asked to do this. Fortuitously it led to membership on other important committees mentioned within my statement. The Panel discussed individual cases and I ensured that patients and their families were always at the centreof all discussions.

CJD Therapy Advisory Committee

44. I was a member of the Therapy Advisory Committee I believe, during the years 2002-2019.

45. The Chief Medical Officer set up the CJD therapy group consisting of medical experts, researchers and scientists, to advise the Department of Health on its response to emerging drug therapies for CJD that may be suitable for clinical trials and to minimize transmission risk of CJD and vCJD in health care settings. In November 2006 the Committee set out guidance to on Patient safety and reduction of risk of transmission of Creutzfeldt–Jakob disease (CJD) via interventional procedures.

DoH Tissue Management Group

46. I was a member of this group but unfortunately cannot recall the time frame of my membership.

47. The Human Tissue Authority (HTA) is an executive non-departmental public body, sponsored by the Department of Health. I believe it was managed from Collindale.

48. The HTA regulates organisations that remove, store and use tissue for research, medical treatment, post-mortem examination, teaching and display in public. It approves organ and bone marrow donations from living people.

49. I recall that samples were scarce and only a few samples were stored and used for research during mytime as a member of the group. I recall that researchers contacted them for samples for their research which the committee discussed.

CJD Research and Resource Centre - (Oversight Committee)

50. I was a member of the Oversight Committee but unfortunately cannot recall the relevant time frame.

51. The CJD Research and Resource Centre was established over 40 years ago, by the UK Department of Health and Social Care. It worked in coordination with the World Health Organisation as part of their response to the appearance of vCJD. It operates as a research tissue bank with the express aim of centralising and standardising rare CJD positive biological samples. It promotes the interests of patients and the public in health research to streamline the regulation of research, promoting transparency and ensures that research is ethically reviewed and approved.

52. By 2008, progress in the field of variant CJD diagnostics led to an increasing demand for access to rare variant CJD positive blood samples, and the Centre was designated as a central repository for these precious materials. It was involved in research using scarce and valuable blood taken from ovarian CJD patients.

Advisory Committee on the Safety of Blood, Tissues and Organs – (SaBTO)

53. I believe SaBTO was made up of members from specialist medical committees who discovered issues and would ask the CJD Incidence Committee for their thoughts on particular issues. My involvement with SaBTO was attending discussion meetings as a member of the CJD Incidence Panel.

54. The Committee advises Health Ministers in England, Wales, Scotland and Northern Ireland; the UK Health Departments; the UK Blood services and Transplant service, and the NHS on the most appropriate ways to ensure the safety of blood, cells, tissues and organs for transfusion / transplantation. Its remit includes providing advice on the microbiological safety of gametes and stem cells, in liaison with the relevant regulatory authorities. The Committee provides independent advice on risk management for Ministers, UK Health Departments, UK Blood and Transplant Services and the wider NHS to consider.

55. I attended the SaBTO March 2019 meeting to feedback the CJDSN'sreport I had written, about some documents that SaBTO asked us to review.

56. SaBTO had established a working group that has been examining two specific risk reduction measures for the transmission of vCJD from blood components. The measures were:

    - Importation of plasma for provision to persons born on or after 1 January 1996 and persons with Thrombotic Thrombocytopenic Purpura (TFP); and

    - Provision of platelets collected by apheresis from single donors for provision to persons born on or after 1st January 1996.

Our answers were:

(i) any decision which would increase risk to the public is unacceptable.

(ii) The cost benefit of the proposed changes should not in any way compromise safety of the public when decisions are made.

(iii) It is important that when reporting any decisions made that this be communicated in a sensitive way taking into account, the likely views of

those who have been and who are presently affected by CJD.

(iv) That the language used must be easily understood by a lay person.

(v) Decisions had been made not simply on the grounds of cost saving but on identifying the resultant quality benefits to the NHS patients including those with all forms of CJD.

57. A family representative who was directly affected by CJD, also attended the meeting with me and gave his own response.

58. The SaBTO committee found the submissions from the stakeholders extremely valuable and these along with their decision have been sent to the Government Ministers. Enquiries were mostly about blood infected with hepatitis B & C.

National CJD Surveillance and Research Unit

59. The National CJD Surveillance and Research Unit is based at the University of Edinburgh, located at the Western General Hospital, Edinburgh. The unit'saims are to monitor the characteristics of all forms of CJD, to identify trends in incidence rates and to study risk factors for the development of disease. During my time as Co-ordinator, I have worked closely with the Unit and referto these occasions within my statement.

60. The CJDSN works closely with CJD Support Networks in America, Australia, Japan, France, Italy, Mexico and Israel and the CJD International Alliance.

Section 4: Research and investigations

1. **Describe, and provide details of, and any investigative or research work you have undertaken that is relevant to the Inquiry's Terms of Reference.**
2. **Outline the information or material that you found through your investigative efforts and/or research.**
3. **Describe the efforts that were involved in obtaining the information or material referred to in question 9 above.**
4. **State whether there is information or material that you were unable to**

obtain access to during your investigative or research work and if so, provide an outline of what you were seeking but were unable to obtain.

80. In about 1996, it was identified that accurate information on CJD was needed, written with lay people in mind. I worked with my colleagues at the National CJD Surveillance and Research Unit and the National Prion Clinic to develop a series of factsheets on eachstrain of CJD, a booklet on Prion Disease and others. These include: CJD and Prion Disease; Sporadic CJD; Variant CJD; Genetic CJD; Iatrogenic CJD; Aggressive Behavior in CJD; the Autopsy in Patients with suspected CJD; vCJD and blood transfusions; Social Workers' Guidelines(England).

81. In 1997, it had become obvious that Social Workers were struggling with CJD. My colleagues at CJDSN and I worked with the Directors of Social Services to develop national guidelines for Social Workers. We also worked with the Queen's Nursing Institute to develop information and nursing guidelines for CJD as well as prompting the Department of Health to produce CJD Health Guidelines.

82. In 1999, I was asked to work with the World Health Organization (WHO) to produce World guidance for CJD.

83. In 2005, to recognise ten years of the CJDSN, I was involved in a research project in conjunction with Lancaster University. The project was to focus on the information, support and care needs of families affected by CJD. The research was launched at the International Conference in March 2006 The findings of were announced at the CJDSN's AGM in November 2006.

84. In March 2007 I attended at the UK Health Protection Agency (HPA) Laboratories in Colindale, London where they were testing 100,000 tonsils which had been supplied by hospitals after operations throughout the country since 2003 to assess the spread of vCJD. At that time, a fourth case of iatrogenic vCJD had been reported. The person had received blood nine years previously from a person who later was found to have vCJD.

85. In September 2009, I was sponsored to attend at a Scientific conference, NeuroPrion 2009 held at Thessaloniki in Greece. 800 researchers from all over the world who were working on prions and related diseases and patient support

attended the conference. Presentations were given on areas of functions and cell biology of PrP, diagnostic, therapeutics and decontamination, basic mechanisms of neurodegeneration and pathology, enigmatic N2 functions and cell biology of PrP. I recall being encouraged that there was such a breadth and depth of research being undertaken by so many committed researchers from all over the world.

Section 5: Individual campaigning activities

5. **Outline the aims and outcomes of any campaigning activities that you have undertaken as an individual insofar as relevant to the Inquiry's Terms of Reference;**

6. **Describe the various campaigning activities you have undertaken, including meetings, demonstrations, complaints and letter writing in relation to clinicians; NHS bodies; blood transfusion services; pharmaceutical companies; financial assistance schemes; government ministers; MPs, MSPs Assembly members or MLAs; and/or government departments and civil servants;**

7. **Describe the response (if any) that you received to the activities described in paragraphs 12 and 13, identifying who responded, when they responded and what the response was;**

8. **What involvement have you had with the media as part of your campaigning activities? Identify, if you are able, the media outlet and the timeframes of the media output, and outline the nature of your involvement;**

World Alzheimer's Congress 2000

86. I presented an education session on CJD at the World Alzheimer's Congress in 2000 in Washington DC. The three-week congress attracted 5,000 delegates from 50 countries.

BBC news article 2001

87. In 2001, the BBC covered a story on the sharp increase in the number of cases

of vCJD and the increased likelihood of people in the north of England and Scotland contracting the disease. In the programme, Professor James Ironside of the vCJD Surveillance Unit at Edinburgh University commented that it was difficult to tell how the disease would grow in the future, because ofthe uncertainties associated with the disease, the unknown incubation period and genetic factors.

88. In respect of mechanically recovered meat (MRM),the Spongiform Encephalopathy Advisory Committee (SEAC) had spent several years asking food companies how much 'mechanically recovered meat' (MRM) was used in the past, as they believed this type carried the most risk of passing on BSE.

89. The Food Standards Agency (FSA) had launched a new investigation to try to extract information from the industry, but I had serious doubts over the role of the FSA. My concern was whether the FSA had enough 'teeth' to enforce their efforts to obtain information. There was a real need for openness from every agency at that time to get to the bottom of what was happening. It was important that more information was provided to enable us to gain more knowledge of CJD and to try and be ready if there was an explosion in cases. Bill Jermey, President of the Meat Manufacturers Association told the BBC that while they wished to co-operate, information on where exactly MRM (meat residue left on carcass) had been supplied was not available. The Guardian also covered the story (06/09/2001) and I commented: "*We need constant vigilance on the cases and it's so very important that more information is given so we can gain more knowledge of CJD and try to beready if there is an explosion in the cases.*"

Nursing Times Clinical – 24 August 2004

90. In an article I wrote for the Nursing Times, titled 'Emerging concerns related to CJD' (24/8/2004), I said that it was hoped that at that time the incidence of CJD was in decline, however new findings suggested that people previously thought not to be at risk may be incubating the disease for longer. I wrote about a second death, where it was found upon post-mortem that the abnormal prion protein responsible for the disease was found in the person's spleen and lymph nodes. Scientists at the CJD Surveillance Unit believed it was very likely that the infection was acquired from blood transfusion. The patient had a different

genotype (MV) from previous vCJD patients, suggesting the disease could potentially affect 90% of the population. It also suggested that some people may incubate the disease for longer periods than those who have already become symptomatic. This meant the period over which new cases may occur could be decades, rather than years. My article also provided information on what is CJD, the development of services, care packages and infection control.

London Evening Standard - New CJD Alert Over Blood

91. On 16th March 2004 it was reported in the London Evening Standard that anybody who had received a transfusion since 1980 was barred from giving blood to stop the spread of vCJD. The ban was following a UK case of vCJD from a blood transfusion. The patient was given blood during surgery in 1996 and went on to develop vCJD three years later and died. The general opinion was that the ban was welcomed but considered long overdue. I commented: "I welcomed the ban and was glad that the Government was taking the issue seriously. It highlighted the need for a quick and easy test for vCJD."

The Herald – Diagnosis Dilemma

92. On 19th March 2006, it was reported, in The Herald, that doctors were likelyto be faced with a major ethical dilemma over the introduction of tests for variant CJD which could become available within a few years. It reported scientists were racing to find a reliable method to diagnose vCJD at an early stage as the disease could only be confirmed through post-mortem examinations of victims' brains. I was asked to give my opinion as National Co-ordinator for the CJDSN.

93. I said that people had a right to know if they could have been exposed to vCJD infection and added: "*There is this ethical dilemma that if they are told, you are basically giving them news that there is no answer to, as there is no test in life for CJD and there is no treatment. What it all indicates, is that we are in desperate need of a simple test for CJD and screening tests for blood.*"

The Mail on Sunday

94. In March 2009, The Mail on Sunday raised awareness of minutes of a SaBTO meeting in 2008 relating to the safety of blood, tissues and organs which revealed that experts are considering limited the 'risk reduction option' to those least likely to have been exposed to BSE in the 90s. It was being considered that 'clean blood' sourced from BSE free countries would be offered to vegetarians and children if they needed a blood transfusion. I told the newspaper that I had concerns about the segmentation of clean blood. I considered in the absence of any test for CJD, there is never any proof that someone is completely free from exposure to vCJD and thought that people should not be discriminated against.

Daily Telegraph

95. On 8th February 2010, the Daily Telegraph reported an article about a High Court action arguing that the delay in changes to the Government's compensation scheme in relation to psychiatric injury. It was also argued that it was unfair that the proposed reforms were not retrospective and did not apply to cases where diagnosis was made before 31 March 2020. The article told the story of a lady called Judy Kenny whose husband Deryck was the first person to die in the UK from vCJD resulting from a blood transfusion. Judy was someone I worked with and was a Committee member of the CJDSN. Judy was not told before her husband's death about the contaminated blood transfusion.

Section 6: Complaints to the police, ombudsman or regulatory bodies

9. Please provide details of any complaints that you have made to:

(a) The police;

(b) An Ombudsman;

(c) A regulatory body (e.g. the General Medical Council)

93. I have not made any complaints to these bodies and have nothing to add to

this section.

Conclusion

94. When I first took up my post, CJD was a very rare disease with many doctors never seeing a case.

95. When vCJD was first identified this changed. It became a very high-profile disease with lots of publicity (similar to the pandemic in 2020). The response by health and social care services and authorities was totally sporadic and uncoordinated, with little or no information on this very rare disease.

96. Now the services for all types of CJD are well co-ordinated, with good information and support for patients, families, and professionals.

97. These services are now available in most countries throughout the world, supported by CJD Support networks. I am pleased that I was able to help these groups grow.

98. I believe that during my time with the CJDSN I have contributed to these achievements,

Statement of Truth

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

Signed...

GRO-C

Dated... 12 April 2021.....