

Witness: Sir Robert Owen

Statement Number: **WITN6441001**

Exhibits: WITN6441002-7

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**WITNESS STATEMENT OF SIR ROBERT OWEN**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 9 April 2021. It is structured to address the specific questions raised by the Inquiry in its request, and should be read alongside the Trust Deed that governs the vCJD Compensation Scheme, a copy of which I have sent with this statement.

**Section 1: Introduction**

1. This is the witness statement of Robert Michael Owen of [REDACTED] **GRO-C**, Cornwall [REDACTED] **GRO-C**, date of birth [REDACTED] **GRO-C** 1944. I was called to the Bar in 1968, and was in independent practice at the Bar from 1969 to 2000. In January 2001 I was appointed to the High Court Bench from which I retired in September 2014. Prior to my retirement I had been appointed to chair the Public Inquiry into the death of Alexander Litvinenko, a role that I continued to discharge until the publication of my report in January 2016. In 2015 I was appointed a member of the Independent Parliamentary Standards Authority for a term of five years, and in January 2021 I was reappointed for a further term of three years.
2. I make this witness statement in my role as chairman of the vCJD Trust, a position to which I was appointed in 2001. I have not provided any evidence nor been involved in any other inquiries, investigations or criminal or civil litigation in relation to vCJD in blood and/or blood products.

**Section 2: Establishment and Operation of the vCJD Trust**

3. In October 2000 the Secretary of State for the Department of Health announced that the Government would pay compensation to the victims of variant Creutzfeldt Jakob Disease (vCJD) and their families. Consultations with representatives of the families affected by vCJD were held; and details of the compensation scheme were announced on 1 October 2001, the Government committing the sum of £67.5 million to provide compensation for the first 250 cases of vCJD.
4. Those involved in the negotiation of the terms of the compensation scheme and of the Trusts set up for its implementation were:
  - representatives of the first 117 families affected by vCJD who in turn were represented by Irwin Mitchell LLP;
  - representatives of the Department of Health;
  - Justin Fenwick QC and Stephen Irwin QC instructed by the Department of Health and Irwin Mitchell respectively;
  - Suzanne Marriott, a trust lawyer at Charles Russell Speechlys.

Neither I nor any of those subsequently appointed trustees of the vCJD Trust played any part in the establishment of the scheme or of the Trusts set up for its implementation.

5. My understanding is that it was agreed at the outset that as the likely number of cases was uncertain, the Government would review the Scheme if the total exceeded 250 victims. To date (June 2021) the Trust is aware of 186 victims.
6. The fund was divided into the Main Fund to which £62.5 million was initially allocated, and the Discretionary Fund to which £5 million was initially allocated. Two interim Trusts were set up to enable payments to be made to victims and their families as a matter of urgency before the vCJD Main Trust Deed was finalised. The vCJD Main Trust in its original form was signed by the Trustees on 15 March 2002. The interim Trusts were then closed. I attach as **Exhibit RO1** the current Trust Deed and First, Second, Third and Fourth Deeds of Variation and Amendment.
7. Under the terms of the Trust Deed (clause 34.1), the Trustees are required once in every calendar year to consider whether their powers are adequate to enable them to act in the best interests of the beneficiaries. As a result and on a number of occasions since its inception, the Trustees have proposed changes to the Scheme principally in order to streamline its operations and/or reduce costs. These are summarised in the documents at **Exhibit RO1** mentioned above. The fourth Deed of Variation and Amendment is currently being considered by the DoH as its consent is required for the further change that we, the Trustees, now propose (see paragraph 26 below).

8. In early 2010 the Department of Health (DoH) agreed to a proposal by the Trustees to simplify the Scheme; and a revised Trust Deed was signed on 12 February 2010. The revised Trust Deed contains two versions of the Scheme, the first applying to victims diagnosed on or before 30 March 2010, and the second applying to victims diagnosed after 31 March 2010.

### **Appointment of Trustees**

9. I was appointed to chair the vCJD Trust by the Secretary of State for the Department of Health at its inception in 2001. The Trust Deed provides (paragraph 19.5) that the chair must be or have been a High Court Judge. To the best of my knowledge the invitation to take up the appointment was extended in part as a consequence of my experience in personal injury litigation, and in particular having had the conduct of multiparty litigation brought against the Medical Research Council on behalf of a cohort of approximately 2000 young men and women who had been treated with human growth hormone derived from pituitary glands harvested in the course of post mortem examinations. A number of the cohort developed Creutzfeldt-Jakob Disease (CJD) at a young age; and it was established in the course of the litigation that the human growth hormone with which they had been treated must have been derived from a pituitary gland or glands from a person or persons who had died from CJD. In consequence I had become reasonably well informed about CJD.
10. Save as indicated above, and that to my knowledge Irwin Mitchell LLP were involved in the relevant discussions, I do not have any knowledge as to the process that preceded my appointment.
11. The remaining six original trustees were appointed by the Secretary of State; but I recall that I was consulted both as to the requisite expertise and as to the individual appointments. First and foremost it was decided that there should be two 'family members' to represent the victims and their families. Their contribution to our work, both in terms of their personal experience and as a channel of communication with the victims and their families, has been essential. In addition it was decided that it was important to have neurological, nursing and legal expertise.
12. The original Trustees were:
1. Chairman - Sir Robert Owen - High Court Judge
  2. [REDACTED] - family member
  3. [REDACTED] - family member
  4. Dr David Stevens – consultant neurologist

5. Ms Vicky Vidler – nursing expert
  6. Ms Elaine Motion – Scottish solicitor
  7. Mr John Melville Williams QC
13. Clause 19 of the Trust Deed makes provision for the re-appointment of Trustees. It provides that all Trustees, including the chair, shall be appointed or re-appointed for a term of 5 years. When a Trustee's period of appointment expires, or he or she resigns, the remaining Trustees may re-appoint the departing Trustee or appoint a new Trustee. In practice, when the relevant period of appointment has expired, the retiring Trustee has been asked whether they wish to be reappointed, and their request has been voted on by the remaining Trustees.
14. At clause 19.4, the Trust Deed makes provision for the appointment of new Trustees:
- “...the trustees shall unless in their reasonable discretion they consider it appropriate to do otherwise, use all reasonable endeavours to ensure that any person appointed as Trustee in succession to a retiring Trustee has similar professional or other qualifications to those of the retiring Trustee and for that purpose may consult with the President of the Royal College of Nursing, the President of the Royal College of Nursing, the President of the Law Society, the President of the Scottish Law Society, the Chairman of the Bar Council, the Chair of the Human BSE Foundation or any other relevant person or body as they consider appropriate”.*
15. It has been necessary to appoint four new Trustees since the Trust was set up:
1. [REDACTED] **GRO-A** replaced [REDACTED] **GRO-A** in June 2007;
  2. Angela Westoby replaced Vicky Vidler in February 2009;
  3. [REDACTED] **GRO-A** replaced [REDACTED] **GRO-A** in February 2010;
  4. Richard Vallance replaced John Melville Williams, who died in October 2011. He was appointed in March 2012.
16. On the two occasions on which a family Trustee has been recruited, the existing Trustees consulted the Human BSE Foundation, and in relation to the replacement of a nursing specialist, the President of the Royal College of Nursing. On each occasion there were very few applicants; and I have real concerns about finding suitable candidates as and when it becomes necessary to replace any of the current Trustees.
17. The Trustees are entitled to be remunerated for their work for the Trust as set out at clause 27 of the Trust Deed:

*“The Trustees shall be remunerated...at a rate equivalent to that payable under the standard scale applicable to non-departmental public bodies appointed to advise the Secretary of State and shall be entitled to be indemnified and reimbursed out of the main fund...in respect of all expenses and liabilities properly and reasonably incurred in respect of or as a result of their Trusteeship...”*

Historically we have each been remunerated at the rate of £400 per meeting and £100 per hour of preparation, together with reimbursement of the cost of travel to London and, where appropriate, accommodation.

### **Administration of the Trust**

18. When the Trust was set up, I considered whether to engage permanent administrative staff. I decided not to do so for a number of reasons. First, it was not possible to predict either the volume or the pattern of work in the long term, and therefore both the number of staff and accommodation that would be required. Secondly, the immediate task facing the Trustees was to determine claims under the Scheme in relation to the 117 cases then in existence. That required immediate and very substantial administrative assistance. The administrative work in preparing claims for consideration by the Trustees bore marked similarities to the work undertaken by solicitors in the conduct of PI claims, and I therefore decided to engage solicitors both to undertake the necessary administrative work, and where necessary to provide legal advice.
19. On the establishment of the Trust Charles Russell Speechly LLP was instructed to act as its Secretariat and legal advisers, as well as to manage the finances, accounts and tax affairs of the Trust. In 2010, and following the move of the team that had the conduct of the business of the Trust to Fieldfisher LLP, the latter firm was instructed to act for the Trust, save in relation to advice on trust law, payments and tax, as to which the Trustees have continued when necessary to instruct Charles Russell Speechly. To the great benefit of the Trustees in the discharge of our duties, the team involved with the work of the Trust at both firms has remained relatively static. Richard Vallance, the partner who from 2001 to 2012 headed the team both at Charles Russell Speechly and subsequently at Fieldfisher, following his retirement replaced John Melville Williams QC as a Trustee, giving strong continuity which has been of considerable benefit given the complexity of the Scheme and the reducing workload over the 20 years for which the Trust has been functioning, a point to which I shall return.
20. The role of the Secretariat is to organise meetings of the Trustees, where necessary to investigate claims, to prepare the extensive paperwork required for their consideration

and determination, and to implement decisions made by the Trustees. An important element of the work is to maintain comprehensive records of the many hundreds of claims that have been made and determined so as to ensure consistency in decisions. Given the time period over which the Trust has run, the work of the Secretariat has allowed the Trustees to check back quickly on any prior decisions and the principles which underpin them which has allowed the panel to ensure this consistency.

21. The Secretariat also provides legal advice and guidance as to the interpretation and application of the Trust Deed. Neither I nor any of the other Trustees received any formal induction or training at the time that the Trust was set up. However, Charles Russell Speechlys provided the Trustees with a Code of Practice, which sets out helpful guidance as to their fiduciary responsibilities, a copy of which I attach as **Exhibit RO2**.
22. The Secretariat has also assisted many family members who have chosen not to instruct solicitors in the preparation of their claims, which has on occasions been a particularly demanding task.
23. In the 20 years of the existence of the Trust, the Trustees have held 66 meetings, and have considered claims relating to 186 Victims of vCJD. At our first substantial meeting we considered claims relating to approximately 100 of the 117 cases of vCJD then identified. This took place over the weekend of 26/27 September 2002 and given the volume of work, was necessarily residential. At that stage there was no reliable basis upon which to predict the future incidence of vCJD. In fact the worst fears have not been realised, and there have since been only a further 69 cases. After the initial meeting we met when necessary to determine claims, which depended on the incidence of deaths attributable to vCJD. As the incidence reduced, so too did the frequency of meetings. No new cases of vCJD have arisen since 2016, and in consequence the workload has reduced to the present situation in which we need only to meet about once a year to deal with any outstanding claims, to discharge our obligation under the Trust Deed to review its provisions annually and to make decisions as to investment of the residual fund. It should be noted that we are advised that the possibility of a second wave cannot be ruled out.

### **Section 3: Relationship between the vCJD Trust and the Department of Health**

24. Save to the limited extent set out below, the Trust is entirely independent of the Department of Health (DoH) and any other organ of government. Whilst the original

Trustees were appointed by the Secretary of State, he or she plays no role in the appointment of replacement Trustees. The DoH does not exercise any involvement in the operation of the Trust, which is governed by the provisions of the Trust Deed. Thus the DoH does not have any involvement or influence, direct or indirect, in relation to:

1. any policies adopted by the Trustees;
  2. the manner in which the Trust discharges its responsibilities to the beneficiaries;
  3. the type of applications that the Trust should grant; and
  4. the quantum of any claim.
25. The Trustees are under no obligation to report to the DoH. As a matter of courtesy the Trust has historically informed the DoH, usually by letter, on an approximately annual basis of the number of those diagnosed with vCJD, the sums paid in compensation, the expenses incurred in administering the Scheme, and any matters of concern to the Trustees.
26. The only direct involvement of the DoH in the discharge of their duties by the Trustees arises under clause 34.1 of the Trust Deed that provides that where they propose to amend or vary its terms, they are required to seek the written consent of the Secretary of State.
27. Although independent of the DoH save to the limited extent set out above, the Trustees have, and always have had, a good working relationship with the DoH. My point of contact has been the Secretary of State. Charles Russell Speechly and latterly Fieldfisher have been in reasonably regular contact with various officials within the Department. There have been occasional meetings between Trustees and such officials usually arranged for a specific reason, most often the variation of the Trust; and the agenda for such meetings has been set by the Trust. I have met the Secretary of State on a few occasions, but not for some years.

#### **Section 4: Funding/Finances of the vCJD Trust**

28. As indicated above the Trust was at the outset provided with funding in the total sum of £67.5 million with which to compensate the first 250 victims and their families. At an early stage we made representations to the DoH seeking an increase in the Discretionary Fund

as we were concerned that as it stood it could be inadequate for compensating claims under the Scheme for psychiatric injury, 'particular emotional hardship' and 'particular financial hardship'. The request was refused, but instead the DoH agreed that we could transfer £3 million from the Main Fund to the Discretionary Fund, with the consequence that the Discretionary Fund was increased to £8 million.

29. No further funding has been supplied by the DoH. Nor do we have any other sources of funding, save for income earned on the unused balance of the fund. I have no knowledge as to how the figure of £67.5 million was arrived at. As observed above, I was not involved in the negotiations that preceded the establishment of the Scheme.
30. In accordance with the provisions of the Trust Deed (clause 34.2) the Trustees have invested the funds held by the Trust on expert advice. The nature of the investments have varied over the period that the Trust has been in existence. At **Exhibit RO3** I attach a financial summary setting out the total sum paid as compensation under the scheme, the total cost of administering the scheme, the gross investment income, the tax paid on the investment income and the current value of the funds held by the Trust.
31. In short we have paid out approximately £41.7 million in compensation in relation to 186 victims. We still hold approximately £18.7 million. There have been no new victims since August 2016. We are therefore reasonably confident that even if there is a second wave of victims, which is considered by some experts in the field to be a possibility, we will be able to meet any further claims up to the maximum of 250 from the funds that we hold. We have not sought any further funding nor do we anticipate doing so.
32. As can be seen from the financial summary at **Exhibit RO3**, the net cost of running the Scheme since its inception has been approximately £6.65 million over 21 years. As to that, there are two important points to be made. First the administrative costs have not reduced the compensation to which claimants have been entitled under the Scheme, although we have necessarily had to take account of the funds available to us in setting levels of compensation under the discretionary heads of claim (see paragraph 54). But secondly the Trustees have nevertheless from the outset been acutely concerned at the cost of running the Scheme, as its complexity in its original form made it very expensive to administer.
33. Over the years, the Trustees and its Secretariat have taken several steps to cut the Trust's operational costs. The most significant simplification of the Scheme was in February 2010, when the Trustees resolved to remove many of the "Discretionary" awards within the Scheme, whilst increasing the quantum of some of the other 'fixed'



awards. This streamlined the processing of each individual claim and has to some extent reduced the cost of running the Scheme.

34. The Scheme was further simplified in April 2015 when the Trustees adopted a series of measures designed to reduce the administration involved in managing the Scheme. This was prompted by a reduction in the number of new claims. The changes did not require an amendment to the Trust Deed but resulted in a reduction in the number of meetings held by the Trust (they are now held annually), a significant reduction in paperwork and a streamlining of the decision making process.
35. In addition to the changes in February 2010 and April 2015, the lawyers for the Trust have always been acutely aware of the need to keep the legal and other costs of managing the Scheme as tightly controlled as possible. They report these costs regularly to the Trustees and perform an analysis of compensation and costs incurred for every meeting. There are, however, inevitable costs involved in running such a trust irrespective of the amount of compensation paid (e.g. tax payment, auditing costs, annual meetings). There have been no new Victims since 2016 and relatively few claims made on behalf of beneficiaries of earlier Victims in recent years, and so whilst the running costs have remained relatively static, the amount of compensation paid has reduced.
36. Clause 30 of the Trust Deed requires that the Trust's accounts be audited each year by a firm of chartered accountants, and that the accounts are made available for the public to inspect. The audit includes a review of the paperwork that provides a record of the decision making process. The review provides an independent and transparent means by which the actions of the Trustees can be monitored.

## **Section 5: Relationship with the National CJD Research and Surveillance Unit (NCJDRSU)**

37. The Trust has had a close working relationship with the NCJDRSU. Whenever a diagnosis of CJD is suspected, the treating clinician is obliged to notify the NCJDRSU. When the clinicians at the NCJDRSU suspect 'on the balance of probability' that the individual is in fact suffering from vCJD, they ensure that the 'Victim' and/or his/her family are made aware of the vCJD Trust and the possibility of compensation. Thus the NCJDRSU operates as a 'catch all' for all cases of vCJD; and in consequence the Trustees are not aware of anyone who has suffered from vCJD who has not been brought to the attention of the Trust.

38. **Clause 1.12** of the Trust Deed requires the Trust to seek confirmation from the NCJDRSU in writing that a claimant:

*"is or was on the balance of probabilities a Victim of vCJD..." and "...that he contracted vCJD as a result of (i) exposure to bovine products purchased in the United Kingdom...or (ii) otherwise as a result of exposure the United Kingdom to BSE or vCJD".*

39. The Trustees are entitled to accept as sufficient evidence of the 'residency requirement' the fact that the Victim was present in the United Kingdom for periods amounting in aggregate to not less than five years between 1982 and 1996.

40. Before the Trust can consider any claim, both points must be confirmed in writing by the NCJDRSU. In other words, the NCJDRSU acts as a sort of "gatekeeper" for the Trust, confirming both the diagnosis and residency requirements of the Trust Deed. This provision has been vital for the smooth running of the Scheme, and works extremely well. It is a simple and clear means of establishing eligibility.

41. As indicated above, potential beneficiaries are usually made aware of the existence of the Trust by the NCJDRSU, although on occasion an individual will contact the Trust directly having found the Trust's website. Once the Victim, his or her family or legal representative has contacted the Trust, the Secretariat seeks confirmation from the NCJDRSU that the diagnostic and residency requirements have been met.

42. The Trust's contact at the NCJDRSU is and always has been Professor Richard Knight.

## **Section 6: Engagement with the Beneficiary Community**

43. The family Trustees were and, to my knowledge still are, involved in the BSE Foundation which supports the beneficiary community. Their experience and insight into the disease, and the needs and the wishes of the beneficiary community, have always been vital to the success of the Scheme and to our consideration of each and every claim.
44. When the Trust was set up I held an open meeting for the beneficiary community which was well attended. At the meeting I sought to explain the Scheme and how it was going to be implemented. To the best of my recollection it took place in late 2001, and at the end of September 2002 the Trustees met to consider claims relating to approximately 100 of the 117 victims and their families, all of which had, to the best of my recollection, been submitted by Irwin Mitchell LLP, who had negotiated the Scheme with the DoH. We have not since thought is necessary to hold meetings of the beneficiary community, not least as two of our number are family Trustees. But as I have mentioned earlier in this statement, the Trust's Secretariat have had direct contact with the many family members who have chosen to submit claims without instructing independent solicitors, to whom they have provided every assistance.

#### **Section 7: Eligibility**

45. The Trust Deed sets out in detail the requirements that must be met by any Victim or beneficiary seeking to claim under the Scheme. The initial eligibility requirements are set out at **clause 1.12**, which defines a "Victim". In simple terms, an individual is defined as a "Victim" if the NCJDRSU confirm in writing that, on the balance of probabilities, he or she suffers or suffered from vCJD, and that he or she lived in the UK for periods amounting in aggregate to not less than five years between 1982 and 1996.
46. It follows that we do not require medical reports as to the diagnosis of vCJD. Medical reports are only required to substantiate claims for psychiatric injury by those qualified to claim under the Scheme, although such claims were removed in the 2010 amendment to the Trust Deed.
47. The eligibility requirements for the different types of claim under the Scheme are set out in detail in the Trust Deed, which has always been available to the public on the Trust's website. I have set out a summary of such claims and their eligibility requirements in the table attached, **Exhibit RO4**. None of the claims are means tested, nor are a beneficiary's circumstances or household income taken into account.
48. The eligibility requirements and their procedural requirements have not changed since the Trust's inception, save insofar as some discretionary claims were removed by the

amendments to the Trust Deed discussed above, and the size of other awards increased to ensure that the total awards given per Victim Group remained broadly the same.

49. The Trust Deed does not stipulate a "burden of proof" save in relation to confirmation by the NCJDRSU that a victim suffered from vCJD. Otherwise every applicant has to meet the requirements set out in the Trust Deed. As stated above the only evidence required to establish initial eligibility, i.e. evidence in respect to a Victim's diagnosis and residency requirement is a letter from the NCJDRSU, which the Trustees (via the Secretariat) obtain from Professor Knight. Following confirmation from the NCJDRSU, those seeking compensation must complete an application form, and are provided with guidance notes as to making a claim. Copies of an application form and some of the available guidance notes are attached at **Exhibit R05**.
50. Where an application is incomplete, the Secretariat will request additional information or evidence. No claim is rejected simply because there has been a failure to supply supporting information or evidence.
51. Applicants are asked to provide a family tree with their Application, so that the Trustees can ensure that all relevant family members of the Victim, who may be eligible for compensation, are contacted to ask whether they wish to claim. In some cases it may emerge that there are valid reasons why a family member should not be contacted. Such inquiries may have to be pursued with considerable sensitivity.
52. There are no special or additional requirements for Victims who are thought to have contracted vCJD as a result of receiving infected blood or blood products. In particular, there is no requirement for them to provide evidence of receipt of such blood.
53. The Trustees exercise some discretion as to what evidence is required for some types of claim. For example, the Trustees resolved at an early stage that we would require invoices or other evidence for claims for expenses over £300, but not for claims below that level, and that we would not require documentary evidence for claims for funeral expenses below £3,000.
54. The awards for the Basic Sum and the minimum multiplicand used to calculate dependency awards have been increased broadly in line with CPI since the Third Deed of Variation and Amendment was signed on 22 May 2012. The Basic Sum is currently £141,400 for Victims diagnosed after 31 March 2021.

55. Once contact has been made and the eligibility requirements for the Victim confirmed, the Trustees must then establish the identity of anyone connected to that Victim who might be eligible to claim under the Scheme. The Trust Deed sets out a list of "Qualifiers" attached to each Victim, known collectively as a "Victim's Group". Broadly speaking, the Victim's Group is made up of the Victim's extended family and carers. One of the difficulties facing the Trustees is that the total awards that may be made under particular heads of claim, 'Experience for Family', clause 4.1, and 'Fixed sum for Care', clause 4.2, are stipulated in the Trust Deed; and in order to fairly exercise our discretion to distribute the award, it is necessary to identify those 'Qualifiers' directly affected or involved in the care of the Victim.
56. As indicated above (paragraph 52) when considering each individual claim we, the Trustees, have to be satisfied that every possible beneficiary within a Victim's Group has been made aware of their possible entitlement to claim compensation and to confirm with them whether they wish to make a claim. This process is often time consuming and difficult, not least because the recollections of those who have undergone deeply distressing experiences from different perspectives may vary. The process begins with the request for a family tree, and for further information in relation to each member of the family. Where possible, each potential beneficiary is contacted directly to ascertain whether they wish to make a claim, and if they do not they are asked to sign a disclaimer. On the rare occasions where it has proved impossible to contact or trace a particular family member or potential beneficiary, the Trustees request information in relation to the steps that have been taken to find them, and the extent to which that person was involved, if at all, with the Victim's life. The Trustees then take a view as to whether the information provided is sufficient to allow compensation to be paid to the remainder of the Victim's Group without contacting the 'missing' potential beneficiary.
57. In many respects the awards payable under the Scheme are akin to heads of damage in common law claims in negligence. But it has been the wide range of those entitled to claim as 'Qualifiers', and the heads of claim unique to the Scheme, such as awards for 'particular emotional hardship' or for 'particular financial hardship' that have introduced a degree of complexity that has made the scheme costly to administer. It is to be noted that, as at May 2021 we have received a total of 409 claims for psychiatric injury, 217 claims for 'particular emotional hardship' and 45 claims for 'particular financial hardship'. These claims were removed for Victims diagnosed after March 2010 when the Trustees amended the Scheme at that time, but claims brought on behalf of family members of earlier Victims continued for many years thereafter.

58. We also set levels of award in relation to some heads of claim so as to achieve a broad consistency of approach, whilst seeking to ensure that we would have sufficient funds to compensate 250 cases. The levels that we fixed were:
1. Particular Emotional Hardship - £15,000
  2. Particular Financial Hardship – £10,000, £25,000 or £40,000
  3. Carers' Loss of Earnings, £5,000, £10,000, £25,000 or £40,000
  4. Victim's Loss of Earnings, £5,000, £10,000, £25,000 or £40,000
59. Although neither I nor any other Trustee was involved in the negotiations of the terms of the Deed, I understand that the beneficiary community argued against a one-off, fixed payment following a diagnosis of vCJD. Instead, they pressed for a Scheme tailored to the individual needs of each Victim and beneficiary. As a consequence, the original Scheme contained a mix of fixed, discretionary and ongoing claims, some of considerable complexity and in consequence costly to administer. As I explained to the Secretary of State, John Reid, whom I met to discuss the Scheme in October 2002, it is in some respects a model of how a scheme for no fault compensation ought not to be set up. That said, it has been greatly improved by the amendments made in 2010.

#### **Section 8: Claims relating infected blood**

60. As far as the Trust is aware, there have only been three victims who contracted vCJD as a result of infected blood. The claims awarded to these three individuals are set out in the table below:

	Victim 1	Victim 2	Victim 3
<b>Type of Claim</b>			
<b>Basic Sum</b>	£120,000	£120,000	£120,000
<b>Experience (fixed sum)</b>	£5,000	£5,000	£5,000
<b>Care (fixed sum)</b>	£5,000	£5,000	£5,000
<b>Funeral Costs</b>	£2,082.15	£12,786.79	£2,189.85
<b>Real/Personal Property</b>	£2,861.80	No claim made	£1,093.18 claimed £931.36 awarded

<b>Purchased Care</b>	No claim made	No claim made	No claim made
<b>Gratuitous Care</b>	No claim made	No claim made	No claim made
<b>Travel, or Items purchased, for Providing Care</b>	No claim made	No claim made	No claim made
<b>Psychiatric Injury (£5,000 fixed sum per person)</b>	£10,000	£25,000	£10,000
<b>Particular Emotional Hardship</b>	£30,000 claimed (two claims) £15,000 awarded	£60,000 claimed (4 claims) £45,000 awarded (3 claims)	No claim made
<b>Particular Financial Hardship</b>	No claim made	£15,000 claimed Nil awarded	No claim made
<b>Carers' Loss of Earnings</b>	No claim made	£4,000 claimed Nil awarded	No claim made
<b>Victim's Loss of Earnings</b>	No claim made	No claim made	No claim made
<b>Dependency</b>	No claim made	No claim made	No claim made
<b>Professional Costs</b>	No claim made	No claim made	No claim made
<b>Mortgages and Life Insurance</b>	No claim made	No claim made	No claim made
<b>TOTAL</b>	£174,943.95 claimed £159,943.95 awarded	£246,786.79 claimed £212,786.79 awarded	£143,282.53 claimed £143,120.71 awarded

61. I also attach at **Exhibit "RO6"** anonymised Decision Reports in relation to Victims 1, 2 and 3. The Decision Reports document the claims made and the reasons why any claims were refused. I have also provided extracts from the Minutes of the meetings at which the above claims were discussed, although these are heavily redacted because there are many references on the various pages to other Victims not relevant to the Inquiry.

#### **Section 9: Complaints, Reviews and Appeals**

62. Broadly speaking, I believe that the beneficiary community has been satisfied with the operation of the Trust. To the extent that there have been complaints or dissatisfaction, this has usually been related to individual dissatisfaction that a particular claim has been rejected. There have also been a small number of isolated complaints in relation to the procedural requirements of some claims, and in particular in relation to the claims for psychiatric injury (i.e. the requirement to obtain a medical report from a psychiatrist).
63. The Trust Deed does not contain a formal complaints process, and it would be a very time consuming and costly exercise to identify those files relating to claims in which complaints have been made.
64. I recall that in 2006, a beneficiary complained to the SRA in relation to (i) the accuracy of information provided to Victims' families in 2004 regarding whether the DoH had concerns about delays in paying compensation, and the relative sums paid in legal costs compared to compensation paid, and (ii) concerns about a breach of confidentiality in March 2006 when the First Schedule of Confidential Victims' Names was accidentally published on the Trust's website for a short period of time. Neither complaint was upheld.
65. In 2009 a small group of families sought to judicially review the Government's decision to agree to the Trustees' request to amend the Deed (which amendment resulted in the February 2010 Trust Deed). This was heard in early 2010 at the High Court in London. Their argument was that the amendment to the Deed requested by the Trustees should have been more radical, reducing the Trustees' discretion still further, and extending the claim further for Victims who lived longer than the norm. The application failed. Mr Justice Silber concluded that there is no "*free-standing power on the part of the Secretary of State to amend the Trust Deed .... in the absence of any proposal from the Trustees...*" and that even if there were, there was nothing irrational about the Secretary of State's failure to invoke it.
66. I attach at **Exhibit RO7** the Judgments of Mr Justice Silber dated 5 March 2010 and 27 May 2010.



67. Where there have been complaints made by individual beneficiaries, the Trustees, via their representatives at Fieldfisher or Charles Russell Speechlys, have sought to engage with the complainant via correspondence or telephone calls. I and my fellow Trustees have monitored such complaints closely, and are satisfied that such complaints have always been dealt with by the Secretariat in an appropriate manner.

## Reviews and Appeals

68. The Trust Deed makes no provision for a formal appeal against or review of our decisions. But there have inevitably been cases where beneficiaries or their representatives have made representations to the Trust in relation to a particular claim, arguing that it falls within the terms of the Trust Deed and should not have been rejected.
69. All decisions are communicated in writing. We do not impose any time limit to a challenge to a decision; but in practice they are made when the decision is communicated but before the award is paid out. It does not cost a beneficiary anything personally to challenge a decision. Any legal fees incurred by a beneficiary bringing a claim, whether in relation to a challenge or otherwise, are paid for by the Trust, up to a maximum of £3,000 (**clause 7.1**) for claims in relation to Victims diagnosed after March 2010.
70. When a decision has been challenged, the Trustees review it, taking account of any representations or evidence put before them. This has happened on a few occasions throughout the 20 years of the Trust's existence. It would be an extremely time consuming and costly exercise to review the many thousands of decisions the Trustees have made in that time to identify those that have been challenged. However, I can say with confidence every such challenge has been resolved without further action once the rationale for the Trustees' decision has been explained (i.e. that the Trust Deed does not allow us to meet the claim).
71. That said, such challenges have been infrequent largely because in most cases the Trust Deed makes it very clear what is and is not payable under the Scheme. The exception to this has been the provisions in relation to claims for psychiatric injury and 'exceptional emotional hardship' which allowed the Trustees significant discretion in terms of who and what to pay. It is these heads of claim that have caused the most upset amongst the beneficiary community. The Trustees sought to address this issue by publishing the series of Guidance Notes to which I have made reference at paragraph 50 above and some of which are to be found in **Exhibit RO5**.

## Concluding Observations

72. The Trustees are conscious of their duty to hold the Secretariat to account for the administration of the Scheme. They share my view that the Trust has been run most efficiently, and that it has succeeded in achieving its objective, the fair and timely distribution of the compensation fund with due consideration for the devastating effect of vCJD on its Victims and on the beneficiary community.
73. But it has undoubtedly been a costly Scheme to administer, a matter of continuing concern to the Trustees, although the net cost of operating the Trust has been offset to a degree by income derived from investment of the fund.
74. A simpler scheme would have been much less costly to administer, but in my view, there are considerable benefits in operating such a scheme by means of a Trust. First and foremost the decision making has been informed by the involvement of Trustees of relevant expertise, and experience, in particular that of the family Trustees. Secondly, it gave the Trustees independence from the Government, which has been beneficial in terms of gaining the trust of the beneficiary community. Thirdly, and although some elements of the Scheme were unduly complex particularly in its pre 2010 form, the carefully defined provisions governing each head of compensation have ensured fair and consistent decisions over the years, and have kept disputes and complaints to a minimum. Finally, over the lifetime of the Scheme there have been unexpected cases which have raised issues which were never in the contemplation of anyone when the Trust Deed was created (for example, the cost of medical treatments that were hoped to extend the life expectancy of victims and the decision to purchase a house for one of the Victims). The Trust Deed ultimately gave the Trustees the flexibility to make decisions on matters which had not been contemplated when the Deed was first drafted to ensure victims/families were adequately compensated and supported.
75. As I have already observed, some provisions have caused particular difficulty. For example, the definition of "Qualifier" within the Deed (i.e. those who are eligible to claim compensation) is very broad. The fact that someone is eligible to claim does not of course mean that their claim will be successful. But it has been necessary for the Trustees to approach all potential "Qualifiers" in order properly to consider whether any claim that they might wish to make should be paid. This has necessarily been a timely and costly exercise, particularly in cases where family relationships have broken down.
76. A further challenge of the Scheme is that claims never "close". "Qualifiers" are entitled to make a claim at any time, and there is no time limit to their doing so. In practice, this means that the Trustees have, on occasion, received claims from family members of

Victims whose claims were first considered many years before. For example, the Trustees have in the last 18 months been considering a claim on behalf of the disabled daughter of a Victim who died in May 2000. Her claim was first considered (and largely completed) in 2004 and 2005, although additional claims were made in 2006, 2007 and 2008. It remains difficult for the Trustees to plan for the future without knowing whether any particular claim is closed.

77. Another major difficulty within the original Scheme was the discretion afforded to the Trustees in relation to claims for 'particular emotional hardship'. When the initial 117 families negotiated the terms of the Trust Deed, they argued against a lump sum and successfully argued for several "discretionary awards", which would be payable at the Trustees' discretion based on the particular circumstances of the individuals claiming. In fact, it was these elements of the Scheme which proved most costly, time consuming and upsetting to family groups. As will have been apparent, that was a significant factor in the Trustees' decision to simplify the Scheme in 2010.
78. Distributing the awards to individuals after decisions have been made has also been more complex than first anticipated. For example, there has been a need to set up trusts when significant awards have been made to minors.
79. The reality is that it is impossible to please everyone with a Scheme such as this. There will inevitably be people who are unhappy with any Scheme. But the Trustees and I are satisfied the overwhelming majority of claimants and beneficiaries have been content with the manner in which it has been administered.
80. In my view the success of the Scheme has been attributable, to a considerable degree, to the makeup of the panel of Trustees. The mix of experience, skills and personalities has been extremely important; and the inclusion of two 'Family Trustees' was of critical importance both in terms of ensuring that the Trustees understood the real issues affecting claimants, and in creating trust between the claimants and the panel. The breadth and depth of the expertise of the Trustees over the years has been indispensable not only in reaching its decisions but in agreeing general points of principle resulting in guidance notes, some of which have been referred to in the statement. Finally, I also believe that it was vital to employ the services of a law firm with sufficient expertise, experience and resources to manage such a complex and wide ranging Scheme.
81. I hope that this Statement has addressed all of the Inquiry's questions. I have inevitably had to summarise the many aspects of the Scheme as to which the Inquiry has sought information to reduce this statement to manageable proportions. The Scheme has been

operating for over twenty years. In that time, the Trustees have considered claims on behalf of 186 Victims, and many hundreds of "Qualifiers" over 65 meetings. As part of that process, we have created many thousands of hard-copy documents, approximately 250 folders of bundles prepared for the meetings and what is estimated to be in excess of 35,000 electronic documents.

82. If the Inquiry would like further information or documents in relation to any of the issues above, I or Fieldfisher on my behalf will of course be happy to oblige.

### Statement of Truth

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

I understand that proceedings for contempt of court may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief in its truth.

Signed: DocuSigned by:  
**GRO-C**  
E21346D725EB429... Dated: 11-05-2022 | 14:48:53 BST

**Sir Robert Owen**  
**Chairman of vCJD Trust**

**Table of Exhibits**

<b>Exhibit Number</b>	<b>Unique Relativity Number</b>	<b>Notes/Description</b>	<b>Date</b>	<b>Para</b>
RO1	WITN6441002	Trust Deed and First, Second, Third and Fourth Deeds of Variation and Amendment	Various	6
RO2	WITN6441003	Trustees Code of Practice	March 2002	21
RO3	WITN6441004	Financial Summary	N/A	30
RO4	WITN6441005	Table of heads of claim and requirements	N/A	48
R05	WITN6441006	Application Form and Guidance Notes	N/A	50
R06	WITN6441007	Decision report and Extracts from Minutes of meetings for vCJD Victims caused by infected blood	Various	63
R07	WITN6441008	Silber J judgments	5 March 2010 & 27 May 2010	68