

THE COMPENSATION OF THE VICTIMS OF THE CREUTZFELDT-JACOB DISEASE IN THE UNITED KINGDOM

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ABSTRACT

Establishing no-fault compensatory schemes is problematic from both a political and legal point of view. In this essay, I analyse the process that led to the compensation of the victims of Creutzfeldt-Jacob Disease and its variant. The paper shows that, although the diseases present many similarities, the two processes took very different paths because of the different, political environments in which they took place. Moreover, several possible lessons can be drawn from the compensation of CJD victims, which can potentially affect the establishment of future no-fault schemes in the United Kingdom.

INTRODUCTION

From 1985, Creutzfeldt-Jacob Disease (CJD), an invariably, deadly encephalopathy, and its variant form (vCJD) have killed several dozens of people in the United Kingdom. The two forms of CJD are linked to different risks: CJD to the human growth hormone (hGH) treatment and vCJD to the consumption of meat contaminated with the 'mad-cow' disease or Bovine Spongiform Encephalopathy (BSE). Both diseases have both spread to humans, and their victims have eventually received compensation. In this paper, I trace the history of the two processes of compensation, the strenuous litigation of the hGH/CJD victims and establishment of a no-fault scheme compensating the BSE/vCJD victims. I analyse in two separate case studies the processes that have led to compensation within the theoretical framework for the emergence of disputes set forth by Felstiner et al.¹ I then compare the two processes based on the analogies and differences between the two. Finally, I conclude by drawing some lesson from CJD compensation process for future no-fault compensation schemes.

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THE CJD DISEASE

The Creutzfeldt-Jacob Disease is a human transmissible spongiform encephalopathy. The disease was first identified by German psychiatrists Creutzfeldt and Jakob in the 1920s. The disease is extremely rare and is part of a group – the Transmissible Spongiform Encephalopathy – of brain diseases that causes sponge-like abnormalities in brain. Transmissible Spongiform Encephalopathy is associated with accumulation of abnormal prion protein cellular in the brain. Only one case per million people is expected. The disease has a very long incubation period, ordinarily up to 30 years from the time of the exposure to risk factor.

Typically, CJD presents itself as a progressive mental deterioration similar to those seen in cases of Alzheimer's disease. CJD symptoms are several: Agitation, dementia and chronic muscle spasms are some of them. Although scientists are working on experimental treatments, unfortunately no screening test and no cure are available today. In 2003, the High Court concluded that administering experimental therapy to two incompetent patients suffering from vCJD is lawful.² The treatment would be in their best interests having regard to their dire prognosis without therapy and the lack of available alternatives, the Court reasoned. However, nowadays the disease is invariably lethal. On average, patients survive only four months after the disease is diagnosed. The histology of the disease shows Swiss-cheese-like holes in the brain with plaques.

There are four possible vehicles of transmission of CJD. First, CJD may be inherited from family member who were infected by the same. The form of CJD better known as familial CJD, accounts for five to ten per cent of cases. CJD can also be iatrogenic, meaning that it is directly transmitted between people as a result of contaminated instruments, tissue transfer such as cornea, blood, polio vaccine, and tissue-extract transfer, as in the cases of hGH. These forms of transmissions are also very rare, accounting for less than one per cent of cases. The majority of CJD cases are sporadic, ie the causes of transmission are unknown.

THE HISTORY OF hGH/CJD VICTIMS COMPENSATION

The hGH program

The hGH is made from post-mortem pituitaries, inadvertently contaminated with the CJD agent, and now known to have transmitted CJD to a small number of those treated with hGH for short stature. The hGH Program started in 1959 as trial program of pituitary or

'cadaveric' growth hormone by the Medical Research Council (MRC). The MRC is an organization funded by the UK Government – and ultimately UK taxpayers – that promotes research into all areas of medical and related science with the aims of improving the health and quality of life of the UK public and contributing to the wealth of the nation. Up to 1977, the program enrolled approximately 800, and by the mid-1980s, the program has significantly developed accounting 1,800 patients.³ On 1 July 1977, the link hGH/CJD was acknowledged. In 1985, the first hGH cohort member developed CJD. Other two cases were reported in the following months of 1985. By the end of the year, the hGH program was terminated. Most of the hGH patients are within the incubation period, and unfortunately they may develop CJD in the next few years.

Similar programs were implemented in the United States, Australia, Brazil, New Zealand, the Netherlands, and France.⁴ In the United States, 22 hGH recipients have developed CJD. None of them has brought a successful claim in court. In fact, cases have been dismissed because the Federal Government is immune from being sued in courts for negligence.⁵ The US government is in fact shielded from liability by the 'independent contractor' exception of the Federal Tort Claims Act, for the negligence of research entities that, under contracts with or grants from National Institute of Health, conducted a program to treat dwarfism in children with human growth hormone. In France, 74 hGH recipients out of approximately 1,700 have developed CJD. The French Government offered to compensate families of children treated with hGH between January 1984 and May 1985 who contracted CJD provided they agree not to proceed with the litigation over the treatment program.⁶

The litigation

In 1990, the CJD victims and their families organized themselves as a group, the Child Growth Foundation, which served as networking organization for most of the victims, connecting them to other patients, lawyers and physicians. The family members of CJD victims were also active in raising awareness of the disease in the public. As the father of one victims recalls,

I spoke at several briefings that we had at the House of Commons for government ministers and members of parliament. The briefings were cross party and non-political. The meetings were attended by the press and television. We got a lot of publicity from this for our fight.⁷

The victims also brought the first claims to the attention of Irwin Mitchell, a law firm that eventually represented more than 30

families of CJD victims and that also served as liaison firm among the several lawyers who were representing other families, operated as clearing house, and was active lobbying government on behalf of the victims.

In 1992, the plaintiff lawyers signed a Legal Aid Contract with the Legal Aid Board, which is publicly funded system that provides representation in court subsidized or free of charge. To receive Legal Aid, a claimant files an application. To be eligible the applicants should satisfy a two-prong test. First, under the relevant means test, the plaintiffs should show that limited financial resources are available to them. Second, applicants must satisfy the 'statutory merits test' by showing that reasonable grounds for filing a lawsuit are present. If the application is successful, a Legal Aid Contract is signed. Under this contract, the clients do not pay lawyers and are eventually asked to make a contribution to the state. The hGH contract anticipated the financial coverage for costs of the legal representation of hGH/CJD victims. In February 1997, the Legal Aid Board's payments to the solicitors conducting the case amounted to £1 million.⁸

The Legal Aid Board has made payments on account totalling £940,355 to the solicitors conducting the case. The main action has been successful and the court made a costs order in favour of the successful plaintiffs. Depending on the final outcome of all litigation, the board will recover some or all of its costs from the defendants.⁹

A parallel, public debate over the merits and costs of the Legal Aid system was under way, focusing in particular on the overall expenditure of the system was growing (by 62 per cent in the 1991-1997 time frame) even if the percentage of the population eligible to Legal Aid was declining (74 per cent in 1979 and 66 per cent in 1990).¹⁰ Due to the increase economic burden for public pockets, in 1999, Legal Aid system was eventually reformed, and now is no longer available for individuals seeking personal injury compensation, but it is still available to fund group actions.¹¹

The case of Patrick Baldwin was instrumental to obtain Legal Aid funding. In fact, in the first year of litigation, the claimants who had filed lawsuits had died rapidly and their legal aid applications had been consequently dropped. On the other hand, because Patrick Baldwin survived for a time longer than usual after CJD is diagnosed, it was possible to complete the application process before the death of the claimant. This exceptional length of the pre-death period of sickness (he was diagnosed in October 1991 and then died in December 1992) and the fact that two daughters survived Mr. Baldwin made possible for the application process to be completed at the time of his dead, and for his Legal Aid contract to be signed before his dead. As Patrick Baldwin's father recalls,

I went back in late December to Mr. Body to fill in the application forms to apply for legal aid on behalf of Patrick. This was done and application was received in London on the January 5th, 1992. I came up against many problems with this application because they did not want Patrick to receive legal aid, for fear of the case getting into court. Legal aid was finally granted after a long fight on the October 22nd, 1992, which was a very long time to process legal aid.¹²

The lawsuits were filed against the MRC and the Secretary of State for Health under negligence theory. At the same time, the victims advocated for a public inquiry and the implementation of a no-fault compensatory scheme as a substitute for litigation. Facing the Department of Health's rejection of all three calls, plaintiff lawyers were urged to pursue litigation strongly.¹³

The plaintiffs pursued their claims as a group to increase their bargain power and the likelihood to recover damages. As one person recalls, '[s]tick together as a group does not let anyone separate you that way you will win through. That is how we won our case against all odds.'¹⁴ Moreover, from the early stages of the legal battle, 'there was an agreement between the parties that the issues to be tried were sufficiently generic to justify the institution of a multi-party action.'¹⁵

No pre-action discovery took place, because the Department of Health provided all sorts of information and testimony to the plaintiffs (1,250,000 documents were made available),

The judge, Mr. Justice Morland [said] that the Department had 'given full discovery so far as logistically possible and have not withheld any witnesses who could have given worthwhile evidence.' In practice, therefore, the court case was very much like a public inquiry, and I am not convinced that another public examination of these issues would add anything further. Needless to say, in what is undoubtedly a tragic situation, the Department is committed to settling compensation for those who will receive it as soon as possible, as well as offering counselling and support, and financing research into the causes and nature of this condition.¹⁶

The first cases were tried in April 1996 in the form of a 'generic' trial, aiming to adjudicate issues that are common to all claimants. The plaintiffs were divided in Group A, comprising of the patients who had contracted CJD or their families, and Group B, 87 hGH recipients fearful that they might contract the disease. Given the ongoing appearance of new CJD cases, the judge did not set a cut-off date for joining the group. A trial focusing only on generic issues of liability is an exception to the general rule set by the Legal Aid, which provides imposes trying some test cases in group actions. In

the aftermath of the benzodiazepine litigation, '[t]he Board argued that a cheaper way of resolving group claims would be simply to select either a test case or a small number of claims (say ten) and try them.'¹⁷

The defendants conceded medical causation, thus relieving the plaintiffs from establishing the link between the participation in the hGH treatment and CJD. However, the defendants contested that the Department of Health owed and breached a duty of care in relation to hGH recipients. In 1996, the court found that MRC had been negligent from 1 July 1977 in failing to pass on warnings from scientists that the hormone could be contaminated by the infective agent for CJD.¹⁸ The clinicians' committee was deliberately kept in the dark, and the decision to allow new patients to commence the treatment after July 1977 was held negligent. Consequently, damages were awarded only to the eight claimants who had had started treatment after July 1977. The British Medical Journal reported the verdict by saying,

Eight families whose relatives contracted the fatal Creutzfeldt-Jakob disease after being treated with human growth hormone in childhood won the right last week to compensation from the UK government likely to total more than £1m.¹⁹

Claims for the fear of future medical conditions were compensated. Because only a small percentage of patients who had participated in the hGH treatment developed a disease by the time of the trial, claims based on the fear of developing the CJD in future have played a major role in the hGH/CJD litigation. Under the judicial opinion, claimants who show symptoms of psychiatric injury are compensated but damages are not awarded to the 'worried well' who suffer a mere anxiety or distress. The rationale that the Court adopted to compensate CJD claimants fearing to develop the disease is fourfold. First, the court considered that, because CJD was infectious, inheritable, untreatable, incurable and always fatal, it was a disease with unique traits. Second, the Court noted that the number of potential claimants was substantial yet limited. The 1,800 patients were the whole cohort of potential cases that do not create a floodgate argument. Third, the Court found the defendants' blameworthiness 'remarkable' because they ought to have foreseen and did foresee the risks. Fourth, the media interest had increased the likelihood to develop psychological symptoms. The court awarded 'provisional' damages to compensate the fear of developing CJD. Provisional damages are 'given in personal injury cases when the injuries sustained may cause in the future some serious disease or other serious deterioration in the plaintiff's physical or mental condition.'²⁰ Courts may award damages based on the plaintiff's conditions at the time of the trial and allow

the plaintiff to come back within a specified time for a further award if the disease or condition worsens.²¹

No damages were awarded to those patients who had started the treatment before July 1977 – the so-called ‘straddler cases’ – and to those patients – the so-called ‘walking worries,’ – who have not developed CJD symptoms yet but are living in the fear of developing the disease, without regard of whether or not they have developed symptoms of psychological injury. The essence of one of the ‘walking worries’ conditions is captured in a debate in front of the Parliament,

Gavin is one of the walking worried. He is a healthy young man in his 20s and is now 5ft 2in tall. His mother tells me that without the treatment that he has received he would probably not have grown much above 2ft tall, so he gained enormously from the treatment. Nevertheless, he was one of those who received the pituitary gland compound and as a result is very concerned, as are his family. His mother came to see me with great courage, fortitude and dignity, but she also expressed to me her sense of guilt because it was she who encouraged the child to have the treatment and took him to virtually every one of the treatments that he had.²²

The appeal and the after-litigation

After the trial, both parties appealed the verdict to the Royal Court of Justice. The claimants sought to include in the award patients who had started hGH treatment before July 1997,

After the court ruling we then started to fight for the people who were outside of the compensation period. Shortly after judgment was given Mr. Body and the right Honorable David Hinchliffe MP and myself. We had a meeting at the House of Commons with John Horam government Minister of the Department of Health. This was to try and get compensation for the people on the no fault compensation plan which meant compensation could be paid but no blame would be apportioned to any one or any department of health. This was the method used to compensate farmers whose animals died of BSE, I am afraid that we were not successful.²³

In 1997, the leadership of the British government changed hands, from the Conservative Tory party to the Labour Party. Representatives of the plaintiffs asked one more time for a meeting with the new head of the Department of Health, Mrs. Tessa Jowell. ‘[The]meeting was a ... success again as the cross appeal by the government was withdrawn. This gave us the clear way back to the courts again.’²⁴ In

November 1997, the Royal Court of Justice partially reversed the trial court opinion, holding that 'a duty of care was owed to *all* patients.' Consequently, all claimant groups were entitled to damages. The eight 'straddler cases' and the six 'walking worries' cases showing identifiable psychological conditions were eventually compensated. The other Group B plaintiffs, who were not showing identifiable psychological conditions, known as the 'worried well' cases, did not receive compensation. After the appeal, a second segment of trial took place to determine the amount of damages to be awarded. After *quantum* cases are decided, the litigation eventually ended in September 1998 – thirteen years after the first patients became sick.

The scope of compensation of CJD claims that were filed after the 1996 followed the criteria set by the judicial opinions. All cases were assigned to Justice Morland of the Royal Court of Justice by order of the Lord Chief Justice, who since then administered compensation on the basis of a tariff-system of damages for both Group A and Group B plaintiffs. The order states the following,

All proceedings in which the plaintiff claims damages against the Secretary of State for Health in respect of treatment with Hartree processed Human Growth Hormone and who has either: (i) developed CJD or (ii) developed a psychiatric illness as a consequence of learning that they may develop CJD should be commenced by writ issued out of the Central Office of the Queen's Bench Division of the High Court. All such actions shall be transferred forthwith to the Royal Courts of Justice ... All writs, pleadings and orders shall be marked on the top left hand side 'CJD Litigation'. The Senior Master shall be the assigned Master and the Honourable Mr Justice Morland shall be the assigned judge.²⁵

Since 1998, all new claimants who qualify as CJD victim based on the requirements set during the litigation, get an award based on the tariff. Any patient whose treatment with hGH meets the criteria set by the court and who contracts CJD receives compensation in terms similar to those reached for the plaintiffs who took part in the court action. In July 1998, the head of the Department of Health states,

The total cost of damages so far in this case amount to £579,000. There were 37 cases not considered by the court. We shall seek to settle these cases using the criteria established by the judge for determining the calculation of compensation. Because of the varying personal circumstances of those claiming compensation it is not possible to estimate the final cost at this time.²⁶

The British Government motivated its decision to provide compensation on a tariff-based system on legal grounds. In fact, the

Government claimed that the verdict and the appeal clearly had held it liable for damages thus creating a legal duty to compensate. 'Any future claim for compensation for other people who have contracted CJD, however that may have come about, will be considered within the context of the Government's statutory obligations.'²⁷ Mr. Horam commented that, '[w]e acknowledge our responsibilities where negligence is clearly proven, and we shall continue to do so'.²⁸ However, it is also clear that efficiency reasons have played a major. Facing a liability verdict that was not overturned on appeal and raising Legal Aid expenses, which is a program ultimately funded by taxpayers, the Government choose the process that reduced the burden of public packets to the greatest extent. Since 1998, twenty-nine new Group A cases and forty group B cases for psychiatric injury have been compensated. The compensation of hGH/CJD victims has been eventually merged into the CJD Care Package announced in 2000 as part of the compensation arrangement for the victims of BSE/CJD, which will be analysed later.

THE HISTORY OF BSE/vCJD VICTIMS COMPENSATION

BSE and vCJD: Factual chronology

In 1986, a novel prion disease in cattle, namely BSE or 'mad-cow' disease, was diagnosed for the first time. BSE is linked with the practice of feeding animals with a meat-and-bone meal, ie the practice of feeding ruminant protein (meat) to ruminant animals. In 1986 meat-and-bone meals are banned and, in 1988, the British Government imposed a compulsory slaughtering program and compensation scheme for cattle-raisers. The number of cases of disease in the animals reached its peak in 1990. By the end of 1990, 24,396 cases of BSE had been confirmed in the United Kingdom, corresponding to three cows affected with BSE in every 1000 in Britain.²⁹ In 1990, a cat is diagnosed with vCJD. In 1995, the first three human beings die of vCJD, ten years after scientists had warned that BSE could be spread to humans. Eventually, however, on 20 March 1996, the Secretary of State for Health announced in Parliament that a new disease, new vCJD, had been identified in 10 people who had died and that it was most likely related to BSE.³⁰

With few researchers raise doubts of the link between BSE and vCJD, the scientific community shares the view that vCJD likely develops as a result of people consuming products contaminated with nervous system tissue from BSE-infected cattle. The vCJD symptoms are very similar to the CJD symptoms, as described earlier: Patients experience early psychiatric symptoms, earlier loss of coordination and later onset of dementia.

The mass exposure of meat-eaters to BSE-contaminated meat makes predictions about future cases often inconsistent. If some predict as low as 100 cases, others suggest that number of vCJDs to be expected in the future is in the range of the half million cases. In July 2004, a government-funded report suggested that the UK is sitting on a vCJD 'timebomb,' and that an estimate of 3808 individuals aged 10-30 years incubating vCJD.³¹ At the time the compensatory fund was established, the predictions suggested a number much greater of what is today – 136,000 v. 500,000 as predicted in 2000 –.³² As of January 2005, 153 vCJD cases have been diagnosed in the UK. Among the 153 cases, five patients are alive, 106 vCJD diagnoses are definite and the remaining 42 deaths are of probably vCJD.³³ vCJD have been diagnosed on other countries too: Seven in France, and one each in Canada, Ireland, Italy, and the United States.³⁴

Devising a compensation framework: The Lord Phillips Report

Soon after the first deaths, the victim's families organize themselves as a group, the Human BSE Foundation, and seek legal representation from the same law firm, Irwin Mitchell, who had played a leading role in the hGH/CJD litigation. As in the case of hGH/CJD, the Foundation serves as networking group, which is essential given the rapidly-degrading nature of the disease. On 10 March 1996, the then conservative government announces that a probable link between BSE and vCJD has been established. Beef on the bone is soon banned in Britain. The BSE Foundation submits a petition for a public inquiry to Tony Blair, the newly elected Prime Minister, who appointed a judge, Lord Phillips of Worth Matravers, to conduct a public inquiry just few weeks after receiving the petition. Members of the Foundation perceived the announcement 'to be the greatest achievement of the families of victims of Human BSE.'³⁵ The chairman and the secretary of the Human BSE Foundation felt that it had been accomplished with very little support from any others, 'other than, perhaps, the Media, a handful of interested MPs and some eminent scientists.'³⁶ The Inquiry has the following scope:

To establish and review the history of the emergence and identification of BSE and variant CJD in the United Kingdom, and of the action taken in response to it up to 20 March 1996; to reach conclusions on the adequacy of that response, taking into account the state of knowledge at the time; and to report on these matters to the Minister of Agriculture, Fisheries and Food, the Secretary of State for Health and the Secretaries of State for Scotland, Wales and Northern Ireland.³⁷

Although the inquiry was undergoing, the victims and their families filed the first civil claims for damages to prevent the statute of limitation from running thus leaving the door open for litigation at a later time.

In October 2000, after two years and half of investigation, Lord Phillips ends its inquiry and the seventeen volumes of the Report are made public. The main finding of the report is that the government ministers played down the links between BSE and vCJD, and they misled the public about the risks posed by 'mad-cow' disease, thus enhancing the public health consequences of the disease. In reconstructing the history of the disease, the Report points out that BSE probably originated from a novel source early in the 1970s – possibly a single cow or other animal that developed the disease as a consequence of a gene mutation. BSE then developed into an epidemic because of the practice of producing animal protein in the form of MBM and including MBM in compound cattle feed. This resulted in the recycling and wide distribution of the BSE agent. After the government had collected evidence that the disease was spreading onto humans, however, a government communicated to the public the BSE risks in a flawed way. 'The Government was preoccupied with preventing an alarmist over-reaction to BSE because it believed that the risk was remote. It is now clear that this campaign of reassurance was a mistake.'³⁸

The vCJD Trust Fund

This vCJD Trust Fund is a major no-fault compensation scheme by which the British government accepted the responsibility, without an admission of liability, for compensating the vCJD victims and their families. The ground to establish a compensatory scheme is set by the Lord Phillips' Report, which recommends that '[v]ictims of vCJD and their families have special needs which should be addressed.'³⁹ The Report pointed out that,

The unusual problems of the diagnosis, treatment and care of the early cases of vCJD meant that for some of the victims and their families the tragic horror of the disease was made the more difficult to bear by lack of the appropriate treatment, assistance and support.⁴⁰

In the aftermath of the publication of the Report, the British Government announced a US\$1 million care package. In the next few months, the Government conducted discussions and negotiations with the representatives of the families to define the scope, the structure, and the terms of the financial package to be put in place.

On 12 April 2001, an interim Trust fund was announced to give the majority of families, which were in urgent need, an interim payment of £25,000. On 1 October 2001, the Secretary of State for Health eventually announces the full details of the Compensation Scheme as developed by the Government in consultation with representatives of families affected by vCJD. In commenting the Scheme, the Secretary of State for Health accounts the spirit of fairness animating the establishment of the Scheme as follows,

I am pleased [the Department of Health [has] reached agreement on the terms of the vCJD compensation package. I hope that these payments go some way towards recognizing the pain and trauma experienced by victims and their families. vCJD is a national and personal tragedy for those affected. It is right that the families receive the compensation.⁴¹

The Government thus justifies as fair an entitlement to compensation because of a 'national tragedy' had occurred. Although not sitting as Trustees, the lawyers from Irwin Mitchell – the law firm who had represented most of the families both in the BSE/vCJD and the hGH/CJD controversies, took part in the process by commenting early drafts of the Application for Compensation and by providing examples of illustrative claims for care.

The Scheme, administered by a Trust, presents two very interesting features. First, it provides compensation to the first 250 claims for deaths for vCJD to a maximum of US\$80 million. Given the uncertain predictions on the number of individuals who will get sick, the Scheme is devised on an initial cap to the financial coverage compensating a limited number of claims with the possibility to revise it in the future when new scientific information will be available. However, if the number of claims exceeds the 250 cases, its terms will be reviewed based on the best estimates that will be available at that time.

Second, the Scheme also makes a one-time payment of US\$75,000 to the families of the first 250 victims as compensation for the 'legal and other difficulties the first families have had to encounter and the additional pressure they have had to bear.'⁴² Furthermore, even if the revision will expand the compensation beyond 250 cases, none of them is entitled to the one-time payment. This arrangement clearly compensates early claimants for their efforts of commencing and carrying out the often claiming process.

The Trust makes a payment of £120,000, or £125,000 if the diagnosis was reasonably suspected before 26 October 2000, to the victim or his/her relatives who satisfy two eligibility requirements. First, the victim suffers/has suffered vCJD 'on the legal test of the balance of probabilities, which means that the victim was at least 51

per cent likely to have suffered vCJD.⁴³ Second, the victim is/was a resident in the UK for at least 5 years between 1982 and 1996.⁴⁴

On the top of the £120,000, the Trust pays a sum of £5,000 (£10,000 if the diagnosis was reasonably suspected before 26 October 2000) to the victim's family. The Trust may also pay an additional £5,000 for the care provided by family members, and may reimburse the care that has been purchased for the victim, or that has been provided by the family before the implementation of the 2001 Care Package.

In addition, subject to certain requirements, the Trust may reimburse the reasonable costs of funeral expenses, the costs of personal items purchased for the victim, limited alternations of property, and the expenditures incurred in providing care of the alleviating the suffering. The Trust may also compensate the loss of earnings both by a carer as a result of providing care that has cause financial hardship and by the victim if the loss of earnings has caused financial hardship to himself/herself and to his/her dependants. Finally, the Trust may also pay a lump-sum of £5,000 where a family member has suffered an identifiable psychiatric condition.

In case of urgent need, the Trust may make an interim payment before the full assessment of the claim is completed. Interim payments are commonly made to vCJD patients who are still alive, but they can be also made to family members after the victim's death.

The compensation only takes into consideration factors relating with the circumstance of the disease and with the economic impact of the disease on the lives of the applicants. It does not consider factors relating with the employment of the victims, their life insurances, or other factors that would ordinarily considered by courts in assessing damages for personal injuries. Not taking into account life insurance benefits is a remarkable difference between this Scheme and the US September 11th Scheme, which controversially discounts any life insurance award form the final payment.

The victim or his/her family submits an application form, which is downloadable online from the vCJD Trust website. He/she attaches all relevant receipts and documents that can help the Trust assessing the claim. A neurologist serves as Special Adviser to the Trustees and certifies that the applicant satisfies the two requirements for compensation, a diagnosis of vCJD and UK residency.⁴⁵ Furthermore, the Secretary of the Trust is a lawyer who gives limited legal advice to the applicants. Sometimes applicants are advised to seek independent legal representation, and, in limited circumstances, the Trust will reimburse the legal fees.

The lawyers from Irwin Mitchell, which represented the victims in the filing of the first civil lawsuits 1996, continue to act for most of the families claiming under the Trust.

Comparing the two CJD compensation processes

In this paper, I analyzed the process that lead to the compensation of the CJD victims whose disease had been caused by hGH treatment and of the vCJD victims who were diagnosed with the human form of the 'mad-cow' disease. If compared, several analogies between the processes emerge. First, the features of the diseases have similarities. They both cause a deadly encephalopathy, which is not treatable yet. Second, both forms of CJD spread into humans because of public health choices that, years after they were made, they revealed themselves flawed albeit unintentionally. In the case of hGH treatment, the policy reflected the standards set by the scientific community that did not require purification of post-mortem pituitaries – a technique which was refined and mandated only in refined in 1977. In the case of BSE transmission to humans, the permissible of feeding animals with meat-and-bone meal in the first instance proved to be fatal to several dozen of British meat-eaters year after.

Third, and consistently with the premise that the decisions to permit hGH treatment and meat-and-bone meal were 'unintentionally' flawed, in both instances, the British government declined full responsibility for the deaths that occurred as a consequences of their decisions. Therefore, in both cases, the victims had to organize themselves developing a 'naming' and 'blaming' strategies, which eventually led to litigation and to compensation. In particular, it is notable that the same plaintiff firm represented the victims of both diseases, thus contributing to the success of the compensation strategy with its know-how and human capital.

Fourth, in both cases, even if the government denied taking full responsibility of the harms, the victims and their families succeeded in establishing a compensation process that extends to all victims of CJD, provided the requirements set by the CJD litigation and the cCJD Trust are met. The reasons why the government favoured the systematic compensation of all victims lie seem to be practical and political rather than moral. Efficiency plays a great role in the rationale to compensate hGH/CJD victims. After the government had been consistently held liable in court for the damages occurred to hGH patients who were treated before the purification techniques were required, the Lord Chief Justice issued on order mandating that all CJD victims that qualified under the standards set by the courts must be compensated to avoid trials on issues already successfully litigated and disbursements for attorney fees. On the other hand, political reasons have been particularly pressing in the BSE/vCJD process: The political weight of Lord Phillips' call for compensation, the need of the recently-appointed Prime Minister to avoid political pitfalls linked to the actions of previous governments, the need

to provide some relief to families that suffered loss of lives after compensation had been given to farmers who suffered mere economic damages, and the recent lessons learned by the administration that had unsuccessfully litigated CJD/hGH cases.

Finally, in both processes litigation is still a viable option. Under the judicial order granting compensation, hGH/CJD claims have to be filed in court before damages are awarded. In the case of the BSE/vCJD Trust, victims, their families, administrators or executors are not barred from taking proceedings against the Crown or any other body. However, if they do, any sums paid under the Trust must be taken into account in any award of damages.

On the other hand, some of the differences between the two compensation processes are remarkable. The most visible difference concerns the processes that lead to the establishment of the compensation arrangements. While the 'naming' and 'blaming' stages were very similar, the claiming steps took different paths. While both groups of victims requested an inquiry, eventually leading to the establishment of a compensation scheme, only BSE/vCJD victims succeeded in this strategy. By contrast, hGH/CJD victims had to bring their claims to court, go through pre-trial discovery (thus requiring large amounts of time and resources to organize the evidence), to litigate the claims in court, to appeal the partially unsuccessfully trial judge opinion, and to eventually obtain a judicial order granting compensation without litigation for all future claimants who satisfied the requirements for compensation as set by the litigation. Therefore, it was a long and consuming process that eventually compensated all present and future victims only because the claimants were able to succeed in establishing the government liability in court. On the other hand, the government established a compensation scheme for BSE/vCJD victims much earlier in the process. BSE/vCJD victims filed lawsuits for the exclusive purpose of preventing the statute of limitation from running in the case the lobbying strategy for administrative compensation had failed. Moreover, for the reasons already outlined, they were able to receive compensation even in the absence of the government negligence.

Moreover, both groups of victims received damages at a rate very close to what they could be awarded if their cases were successfully tried in court. In fact, both arrangements derive guidance in damage measurements from the traditional tort system, and the compensation level is at (or near) 100 per cent of what might be awarded at common law. However, only the BSE/CJD scheme recognizes claims that would not be recognized in court. It is the case of claims for psychiatric injury by people who would be classified as 'secondary victims' beyond the spatio/temporal proximity required by common law for compensation.⁴⁶

CONCLUSION: THE CJD COMPENSATION PROCESS AND THE FUTURE OF NO-FAULT COMPENSATION SCHEMES

It has been argued that the 'CJD Trust Fund could form a model, or at least may be some sort of precedent or give some guidance, for other no fault schemes in the future.'⁴⁷ Although I agree with this remark, I predict that the CJD Trust Fund or the CJD judicial order in the hGH cases will not become the ordinary means of victim compensation in the United Kingdom as alternative to the litigation of torts claims in courts. As discussed before, I suggest that concerns of fairness played a minimal if no role in the government decision to compensation both kinds of CJD victims. On the other hand, my claim is the reasons are to be found in efficiency and politics. Consequently, I predict that these forms of administrative compensation will not become an ordinary means of victim compensation in alternative to tort litigation in courts in the United Kingdom. My prediction will be soon tested when the issue of compensating the 'new' CJD victims, which have developed the disease as a consequence of blood transfusions from donors who carried the disease, will emerge. In fact, several dozen recipients of blood from blood donors have developed vCJD have been identified. Two of the 50 recipients are known to have been infected. One has since died with clinical vCJD.⁴⁸ If my prediction is true, these recipients of contaminated blood will not be simply entitled to compensation by extending the scope of the CJD Trust. More likely, they will have to bring their claims to courts, show evidence of some government malfeasance, and then lobby for a non-litigation based resolution of their claims.

On the other hand, the described compensation arrangements provide some guidance for future no-fault compensation. First, in both cases, traditional torts litigation provides guidance in setting the level of damage awards. Second, the provisions of the vCJD Trust provide that awards shall not be offset by life insurance and other collateral source compensation. Therefore, awards to claimants who are insured are not reduced if payments form sources other than the Trust are available. By contrast, under the US September 11th Victim Compensation Fund of 2001, '[t]he Special Master shall reduce the amount of compensation determined under paragraph (1)(B)(ii) by the amount of the collateral source compensation the claimant has received or is entitled to receive as a result of the terrorist-related aircraft crashes of September 11, 2001.'⁴⁹ The fairness of this provision has been hotly debated in the States. Certainly, the vCJD Trust Fund sets a precedent for future no-fault compensation schemes in the UK, whereby it is likely that future schemes will also follow not offset collateral payments.

Finally, the BSE/vCJD Trust has accomplished both fairness and

efficiency by mandating that the Trustees 'shall ... consider whether the trust powers and provisions ... are adequate to enable [them] to act for the best interests of the beneficiaries' and if the powers are not adequate they may, with the written consent of the Secretary of State, 'amend vary or alter the powers and provisions.'⁵⁰ Along with the initial but reviewable compensation cap to 250 cases, the Trust is a flexible arrangement that allows administrators to assimilate changes in the circumstances of the compensation following the events such as the review of the size of the estimated cases and new developments in case law that could extend or restrict the scope of compensation. Compensatory schemes are often lacking this flexibility, which often proves to be a substantial flaw in the design of the schemes. Therefore, the vCJD Trust Fund sets the example to set up flexible no-fault compensation schemes whereby compensation can be adjusted whenever the predictions of emergence of the disease substantially vary or whenever important changes in the law take place so that parameter of compensation are substantially affected.

NOTES

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