

Written evidence submitted by **GRO-A**

HAS THE THREAT OF ONGOING TRANSMISSION OF VCJD THROUGH BLOOD AND BLOOD PRODUCT SUPPLY BEEN ADEQUATELY MITIGATED?

Here is my reply and experience I am also offering myself as witness to the inquiry committee.

1. My name is **GRO-A** I am a mother of two children, a freelance journalist and campaigner [www.justice.gro-a.com](http://www.justice.gro-a.com). My only son **GRO-A** was killed by the human form of mad cow disease on **GRO-A** 2007 aged just 24 years old. **GRO-A** was a healthy young man, intelligent, handsome, ambitious a rising star in the media. My son worked as a freelance Radio and TV producer/researcher. He worked for **GRO-A** **GRO-A** and a wonderful future ahead of him. In March 2007 **GRO-A** produced his last live national radio broadcast by **GRO-A** 2007 he was blind, quadriplegic, unable to move, unable to eat, weighing less than eight stone, wracked with pain and dying of human BSE. I held my son as he died in my arms and buried him **GRO-A** before Christmas. **GRO-A** and my family had not eaten beef since 1988. BBC 1 documentary DVD, of **GRO-A** **GRO-A** INCLUDED AS EVIDENCE.
2. When **GRO-A** was dying he asked me 'find out who has done this to me mum' always thinking of others he begged 'this must never happen to anyone else ever again.' I promised my son I would do everything I could to get to the truth and protect other families.
3. Over the last 6 years I have crossed the UK and world looking for answers, interviewing many victims, their families, scientists, medics, Ministers those at the very heart of the BSE scandal. I launched the campaign [www.justice.gro-a.com](http://www.justice.gro-a.com) whose goals include an independent criminal investigation into the unlawful deaths of all victims of VCJD, and also for an individual blood screening test for VCJD, treatments and cures. The campaign and families affected want blood donor's automatically screened for human BSE and patient's who attend medical procedures in hospital routinely screened for VCJD. When blood was first screened for HIV the prognosis was terminal but within a short time treatments followed which now allow people with AIDS to live long and productive lives. I believe once a test is implemented funding for treatments and cures will follow. I believe the UK government drags its feet over a blood screening test for VCJD as it does not want to reveal prevalence of human BSE in the UK population. This is short sighted attitude is being used to protect those responsible for BSE and not to protect the human health of the UK population.
4. As well as meeting victims of VCJD who have succumbed to the disease via infected beef products, I have also met and am in contact with 'living victims' of CJD, these people have been told they are 'at risk of developing CJD' due to medical procedures which have exposed them to contaminated surgical instruments, cells, organs. My website has had millions of hits with thousands of concerned citizens emailing me their fears and concerns.
5. Thousands more of us may well be 'living victims' and many of us will be blood donors. As blood donations are also used to make vaccines and many medicines, one donation can have the ability to infect hundreds of people. There have been recalls of vaccines over the years through fear of BSE/VCJD infection, but if a blood donor is not showing any symptoms he/she could still pass VCJD onwards. I believe the DOH are aware of 'healthy carriers' and particularly of one blood donor of many years who remained healthy and has been implicated giving blood to at least two people who have since died of VCJD. This apparent healthy 'pool' of silent carriers could cause a devastating 'second wave of VCJD victims' in

the coming decades. Many victims of vCJD have been blood donors and many of their recipients never traced.

6. All blood bags and blood products in the UK now carry a disclaimer 'at risk of adverse reaction infection, including vCJD' since July 2007. This is not widely known. Warnings are of little use if action is not taken!
7. We face a ticking health time-bomb regarding vCJD being passed on through blood and medical procedures. With the latest HPA Health Protection Agency research stating that '1 in 2,000' may be carrying vCJD' many of those carrying vCJD will be blood donors.
8. Experts at the Select Committee stated that only people from the 'MM' gene group have died of vCJD. I would dispute this as I am contact with parents who have been told by the CJD, Prion Unit and Department of Health officials that 'your child has vCJD is MV genotype and you can receive government compensation, but your child will never be officially recognised as a victim of vCJD.' There are many flexible protocols which are being used to diagnose vCJD cases and this means that victims can disappear from official stats. One 19 year old who died was diagnosed as having 'sporadic CJD with signs of vCJD' because she was a different genotype! These victims are documented in the media and also in my book. MV make up the largest healthy genotype in the UK 53 percent of us will come from this group, so the majority of blood donors will too!
9. I have been offered £120,000 compensation by the British Government, I have refused all monies of a gratuitous payment which is commonly known as a 'no fault no blame' compensation. My investigations have discovered there are many to blame and many at fault. My aim is to have those responsible for the unleashing of BSE on to the UK population accountable in a court of law in the near future. The ticking health time bomb that is the deadly BSE legacy means that our entire Blood Transfusion system is not clear or free of vCJD. I am in contact with yet another family who lost their middle-aged mother to vCJD via a blood transfusion she had in 2002 well after Frank Dobson brought in lecodepletion in 1998. Technology has moved forward in those fifteen years and yet we are still not screening our blood supply for vCJD. The Department of Health will state there is 'no validated' test, well they control validation and also all samples of vCJD victims blood, so scientists outside the UK have great difficulty accessing blood to push tests onwards to validation. The DOH and UK government control all aspects of vCJD research and this is a very dangerous monopoly.
10. I have also met many other victims of vCJD who have received contaminated blood and blood products, and my website has been bombarded with emails from people who have been given a 'at risk' diagnosis out of the blue due to having operations in the same theatres where the previous patient has developed CJD.
11. A blood donor has the ability to infected hundreds of people and we have millions of blood donors in the UK. Every country in the world will not accept Brits as blood donors or anyone who has lived, worked, travelled to the UK between 1980 and December 31<sup>st</sup> 1996. My colleagues who covered 9/11 lined up to give blood to the many victims, but because they were UK citizens or had lived in the UK they were not deemed fit to give blood. They were told 'you are all at risk of mad cow disease so we can't take your blood.' This is the reality of our blood supply in the UK.

12. Myself and many other parents of vCJD victims, have tried to send over our late son's or living son's blood samples to foreign scientists developing blood screening tests and treatments for vCJD abroad. We have been thwarted at every turn by the Department of Health and the authorities. Whitehall keeps a firm and controlling grip on BSE/vCJD research. My findings including the statements I have made above are in my new book **GRO-A** **GRO-A** Amazon best seller which clearly shows a conflict of interest within scientific UK knowledge and UK government policy. Careers, funding, political policies, all come into the mix and this creates a culture or secrecy surrounding many of the facts and truths about Human BSE. This attitude has continually hampered research, treatments and screening tests.
13. I am totally independent and would hope that the committee appoint family members to sit on the inquiry, not just experts funded or salaried by the UK or authorities, not just MPs who may mind their political party whips. Recent family member's who have lost a love one to vCJD and witnessed the disease and its aftermath at first hand, should be an essential part of the Inquiry's process. Too often committees become a place for 'experts to talk' 'big up their opportunities for extra funding,' to 'look good in the media' Whilst the reality and human face of victims and the real cost to the nation's health is lost.
14. Human BSE or Mad cow disease continues to kill people who lived, laughed and loved many of them young men and women in their prime. Government talking heads often loose that humanity and it becomes an abstract disease with dense language, which removes the authorities from their responsibility and duty of care. I urge you to have on board the committee ordinary members of the public/family members that are not handpicked by Whitehall, but, individuals who will challenge, demand answers and honesty. In the past family members have been wheeled out at various meetings overwhelmed or told what to say. I would like to see recent family members affected by vCJD take an active role with influence and respect in the inquiry. The culture of secrecy that allowed, condoned gave BSE full flow into the human food and medicine chain must now in 2013/2014 be eliminated.
15. My campaign supports all scientists and medics who are pushing forward for treatments, cures, screening tests for vCJD, but am aware many of them in the UK are bound by funding, careers, their salaries, unable to be as even handed and open as they could be. This monopoly by the UK Government and many of the departments who created and allowed BSE in the first place should be finally addressed.
16. I also urge the inquiry and committee to speak about BSE and vCJD in simple terms, so often precious scientific language, piles of paperwork, complicated governmental policies and words have been used by Whitehall to hide and conceal instead of support and reveal. I also would like costings of the inquiry to be kept minimal and these also open to scrutiny. Too much has been spent on Mps and experts talking and talking with no action. We need all blood donors to be screened for vCJD.
17. Families who have lost a loved one to vCJD and who have taken the compensation of £120,000 have told me of bullying and intimidation 'don't go to the press, don't talk to your neighbours that your son/ daughter has vCJD.' Others have been told by members from the Department of Health 'your child is dying because you fed them cheap meat'. This is appalling as The UK government had a duty of care and food and medicine deemed safe by the Government should never kill, but it has and continues to do so.

During my investigations I too have been intimidated, bullied and threatened, all of this and more is recorded in my book [GRO-A] I have attached the NUJ the Journalist review of my book.

18. To Conclude:

VCJD has not gone away and continues to kill not just here in the UK but globally. I have recently returned from meeting families affected by CJD in Italy. People continue to die of human BSE due to ingesting infected bovine material during the 1980s and 1990s, according to Professor Collinge there may be incubation periods of 50 years, generations remain at risk. Many of us who may incubate or carry the disease will be blood donors or hospital patients. All have the potential to pass on the deadly infection via blood and medical procedures. We face a secondary wave of vCJD infection via these routes.

One of the most recent victims of vCJD who became infected due to ingesting infected beef during the 1990s or 1980s was a vegetarian. He incubated the disease probably for decades before symptoms appeared. People of faith who cannot eat any part of the cow and also strict veggie have died of vCJD. [GRO-A] died of vCJD a few years ago a young [GRO-C] man who had not arrived in the UK from war torn Bosnia until late 1992 [GRO-A] and his family were awarded the compensation as he had contracted the human form of BSE from food medicines here in the UK. We need to stop more deaths of vCJD through contaminated blood or blood products.

I have interviewed families who have lost a loved one to vCJD who had also been a blood donor, they were warned by the CJD unit and Department of Health officials 'don't tell anyone your child gave blood especially the press or your neighbours.' These family members were terrified by the very officials who were supposed to offer help and support. This is a common theme in my personal and professional dealings with families who have been affected by vCJD. They have been kept isolated by government officials, many bullied this is totally unacceptable.

As a parent who has lost a dearly loved only son to vCJD I have been continually appalled at the behaviour of many government officials present to victims and their families. It's a travesty that I am hopeful an inquiry will address too as this is part of the cankered core that created BSE, unleashing it on an unsuspecting public.

There are thousands more 'living victims' who could decline just like my son, tens of thousands of us now carry vCJD, it's the biggest political and health scandal of modern times and it's finally time for the public to know the whole truth about BSE. I fear that the government will not welcome a blood screening test. It would be relatively cheap to mass screen blood donors compared with the spiralling cost of other safeguards which have limited value.

I fear the UK Government will stall and block any mass blood screening test for vCJD as it would highlight the prevalence of BSE exposure within the population, it would also show the exact source of the original infections. This is a particular can of worms the incumbent Conservative led government do not want to address. With a blood screening test for vCJD available more understanding and funding for treatments and cures would result as would much more understanding of other neurological diseases such as dementia and Alzheimer's.

I would like to give evidence at the inquiry committee meeting and will end this with an extract from my book, [GRO-A] [GRO-A] could be any mother's son, anyone reading this submission. I can supply members of the committee a copy of my book, profits go back to the campaign. I do not want more innocent people dying of human BSE due to contaminated blood and blood products.

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