

Meeting at the department of Health Thursday 22nd July 2010 with Anne Milton MP Health Minister

In Attendance Anne Milton Minister for Public health, Rowena Jecock Head of Blood Policy, Yemi Fagun DOH official Joanne Jones DOH official, Colette Wintle and Carol Grayson.

We have both been asking for meetings with ministers for many years. This meeting came about following a request with CW's long standing contact with Earl Howe. Following an email exchange last weekend, and with his kind assistance, the Minister was "immediately receptive" and agreed to make time for this meeting on Thursday.

The Minister welcomed us and thanked us for attending this meeting which she felt was important in gathering relevant information, which assisted her in having a better understanding of all the issues which have affected all those involved in the Blood Tragedy. It was felt that as all those present in the meeting shared a background in nursing, this was helpful in understanding the issues being raised. She stated that she did not know the full history of events however she realised the seriousness of needing to offer answers and a fair resolution which would reflect the suffering and losses the haemophilia community had endured. As in her previous meeting on Tuesday she confirmed her wish to have the issues resolved and dealt with by Xmas time. The Minister also acknowledged that the haemophilia community was in a unique position in comparison to other disasters.

CW passed a vital document (kindly provided by CG and her late husband) which highlighted the misunderstanding within the DOH on state of knowledge of Non A Non B Hepatitis during the 1970's and 1980's, and when it was known to be "deadly". The Minister was visibly shocked when she read the statement by Dr Rizza quoted from HIV the myth published in 198. She instructed JJ to get their information changed immediately, and reflect this in their responses to any future written communications from the Department of Health. This is a significant move forward. The Minister accepts that a change of language, and understanding, that non A non B was not an inadvertent infection must now be acknowledged which CG and CW have been challenging the DOH on for many years.

CG was asked to discuss the implications of future policy regarding infection controls, examining and comparing past practices and the current safety mechanisms in place. The Minister acknowledged the need to ensure lessons will be learned from the past in this regard, and also for improved future care in haemophilia management. There needs to be a better understanding within the medical profession through creating new regulations. CG passed her dissertation to the Minister to provide a chronological history of bad blood which identified serious safety violation in blood policy. The Minister was happy to receive it, and has now passed this on for a senior DOH virologist to read. CG has requested written feedback.

CW suggested that teaching and educational organisations within the NHS could be better informed if the history of this treatment disaster was taught to health care professionals and doctors. This would help them to understand the specialist needs of people with bleeding disorders and improve the standard of care on offer. CW explained her own experience as a woman with bleeding disorders and how difficult it has been to battle the ignorance and discriminatory reaction from health carers, who are misinformed, judgmental and unwilling to accept health problems that relate specifically to female issues. CG suggested that the contaminated blood disaster should be on the curriculum at medical schools to teach student doctors.

CW discussed the current provision of nursing care available to haemophiliacs within their local communities, when nursing care is required out with their Hospital care, and what additional funding the DOH offer via the NHS to health providers ie; GP's and local PCT's. The Minister stated that if CW was unable to access free 24 hour nursing care she would recommend approaching the local MP for answers, as this should already be available free of charge. CW said she would investigate and report back to the Minister.

CW spoke about some haemophiliacs still being charged for prescriptions despite Professor Ian Gilmore's recent report and recommendations that people with chronic conditions should not be paying these charges. RJ acknowledged this needs to be looked at urgently. Prioritisation of transplants for haemophiliacs was discussed. RJ stated that at present it is only offered on "the basis of clinical need" CW pointed out the comparison of the haemophiliacs in America, who are automatically prioritised for liver transplants because they were infected through contaminated blood, and that many haemophiliacs in this country should be afforded the same courtesy. It

was also pointed out that it was often left too late for haemophiliacs because they are not clinically assessed quickly enough. CG 's husband was used an example.

CW asked the Minister why the department for Works and Pensions are still targeting haemophiliacs, for repeated reassessment for their entitlement to Incapacity and other benefits. The Minister agreed that infected haemophiliacs and affected partners and widows should not be forced to fill in inappropriately worded forms or be subjected to physical examinations to prove entitlement.

CW pointed out that this group should be exempted by the DWP, because the recipients of long term benefits are already known to the DOH and DWP. The Minister has asked YF to contact the DWP to ensure this is stopped.

CG discussed widow' and partners losses. Loss of loved ones, not being able to have children, and the loss of their career. She highlighted that in a number of cases the women carers were also often the main wage earners due to husbands being unable to work. This loss of employment resulted in loss of wages and pension rights. Partners were unable to get life insurance, therefore there was no financial security. In some cases women were forced to sell their home. The financial losses have been significant and CG was keen to explain to the Minister that widows need to be assessed in their own right and not as an appendage to their husband (gender justice).

CG raised the fact that woman in bereavement can often experience physical and mental distress such as depression and post traumatic stress disorder, and cited several known examples of this. It was also pointed out that the Macfarlane Trust and the Skipton fund were not given sufficient monies from the government, to address the financial needs of partners, carers and widows. Although this affected predominantly women we did recognise that some men would also fall in to this category of need. CW also added that if her health deteriorated further, her husband would have to sacrifice his career and if death occurred would have to sell the family home to cope with loss of income and caring for a dependent child.

CG has asked for the government to consider a government apology to Lord Owen for shredding many of his documents which was unprecedented and also to apologise to the family of Virologist Spence Galbraith, who warned the government, of the need to withdraw the US concentrates which were causing

the AIDS virus. His safety advice and opinions were ignored in 1983 when many lives could have been saved.

The Minister thanked CG and CW for coming at short notice and was keen to ensure that whilst it would not be possible to give everyone back all their losses, she recognised that the government's response to this treatment disaster, would have to be reflected in their acknowledgment of the suffering and hardship through a fair settlement. CW and CG reiterated that the community would like the government to implement the Archer recommendations as soon as possible, as this would be seen as a positive response, and perhaps offer closure. CG told the Minister that implementing Archer would mean a great deal to her as she and her late husband set up the initiative for parity with Eire in 1996.

This was a positive and worthwhile exchange of information and is encouraging for the whole community.