

Dear Committee Members,

Re: P- 05-831 Infected Blood Scheme petition

Thank you for communication from Vaughan Gething for which we are very grateful. We would be grateful also to consider representations made in this document in considering any next steps.

The petition was developed and done for a group called Contaminated Whole Bloods UK (CWB).

Looking at the response from the Cabinet secretary, we want to ensure that the purpose and hoped outcomes are understood clearly. The petition:

- Is asking for those infected in Wales receive the same financial support as those infected in England as a MINIMUM. The ideal is that there is equality for all victims, in terms of financial support, across the United Kingdom
- The petition is not requesting that the Special Category Mechanism is simply adopted for those infected in Wales- but that that the scheme is amended to ameliorate the position for those infected in Wales

To illustrate the differential, here is a REAL position of 2 infected people to compare. Both parties would be happy to come and speak the committee or other group directly:

	A (infected in England)	B (infected in Wales)
Date of infection	1991	1980
Location of infection	England	Wales
Current Hep c status	SVR	Hep C virus still active
Support scheme level	Stage 1	Stage 1
Relevant blood support scheme	EIBSS	WIBSS
Treatment	2012 – virus cleared	Health means that not yet possible
Current living location	NW England	NW England
Current Hep C related Impact	Every day significant fatigue, brain fog, unable to live normal life	Every day significant fatigue, brain fog, unable to live normal life
Ability to work	Still able to work full time (with adjustments)	Unable to work due to health (as defined by DWP**) and determined that in the group that unlikely to be able to work even with help
Income from non-blood support schemes	Wages, working FT	Employment support allowance
Income from blood support schemes:		
1) Regular payments scheme pa	£18500	£4500
2) Discretionary schemes top up	£4000	£2000***
Total in Blood Support payments	£22500	£6500

*Sustained Virological response – term used to describe when the virus count is negligible because of ‘successful’ treatment

** Department of work and pensions work capability assessment

*** Person B receives this money from the ‘Caxton Fund’. The fund is historical and doesn’t appear to be available to newly discovered infected people <https://wibss.wales.nhs.uk/eligibility/>

Key points:

- As you can see from the comparison table person A is better off from blood support schemes **by £16,500 per year.**
- If Person B was a new registration not an existing beneficiary, there appears to be no scheme that a lay person can find to receive the £2k discretionary scheme payment. The differential in blood support payments would be **£18,500**
- Person A is arguable in better health because:
 - They have cleared the virus
 - They are still able to work full time
 - The virus was in their system for less time
 -
- Person A is in this advantageous position because of the EIBSS scheme offers far more all-round financial support than WIBSS for some groups of beneficiaries – this is particularly accentuated for those classed at stage 1 with ongoing problems
- Based on the data we have received from EIBSS, we believe that approximately 70 people infected in Wales are impacted in a similar unfair way. Based on this example – and taking the difference as an average, the cost of equalisation would be a mere £1.1m (or 0.01% of what I understand to be the Health budget for Wales (£7.2bn))

CWB UK works to support people across all the schemes in the UK. The ideal position is that all infected people across the UK are supported consistently and effectively.

I would be happy, if needed to meet (or correspond further) the committee or other decision-making body to help with potential options and solutions on behalf of CWB UK. It’s important the assembly hears from ALL voices of those infected in Wales not just the more recognised groups as is the suggestion here <http://record.assembly.wales/Plenary/4912?lang=en-GB#A42264>

Richard Wilkinson/Michelle Tolley

Contaminated Whole Bloods UK

