### Y Gwasanaeth Ymchwil | Research Service

# P-05-831 End the unfairness and discrimination in the financial support for victims of the contaminated

Y Pwyllgor Deisebau | 25 Medi 2018 Petitions Committee | 25 September 2018

## Research Briefing:

Petition number: P-05-831

Petition title: End the unfairness and discrimination in the financial support for victims of the

contaminated

#### Text of petition:

This petition calls on the Welsh Assembly to end the unfairness and discrimination in financial support for all victims of the infected blood scandal for those infected in Wales, by changing the scheme to at least mirror the provisions for those infected in England.

Many categories of victim infected in Wales are potentially worse off under the scheme by £20,000 or more. Thousands of people were infected as result of receiving infected blood or infected blood products given to them by the NHS until at least September 1991. Over two thousand people have already died.

Following devolving of powers, the responsibility for support of victims and their families, for those infected in Wales, sits under the Welsh Assembly. The schemes for support are operated by the Welsh Infected Blood Support service (WIBSS) which is administered by Velindre NHS Trust and NHS Wales Shared Services Partnership (NWSSP) who are ultimately accountable to the Welsh Assembly.

For those infected in England, the comparable scheme is run by EIBSS, ultimately accountable to parliament in London. Even though the victims were all infected by the NHS pre – devolution, the EIBSS and WIBSS have vastly different provisions in financial support. The determining factor as to which scheme you fall under is where the victim was infected not where they live. There are two schemes that those under the WIBSS cannot access. They are called the 'Special Category Mechanism' and 'The discretionary top up scheme'. The net effect of all this is that many categories victim infected in Wales are potentially worse of under the scheme by £20,000, more if they have children, irrespective where of where they live. Two

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people living in say Cardiff, both infected by the NHS, both with the same impact might receive £20,000 difference in support simply because one of the two had the 'good fortune' to be infected in England.

We call on the Welsh Assembly to intervene end this injustice now.

#### **Background**

During the 1970s and early 1980s, thousands of UK patients contracted hepatitis C, HIV, or both, from contaminated blood or blood products. Most of those affected were haemophilia sufferers, whose treatment relied on repeated intravenous infusions of blood clotting factors extracted from donor plasma. At the time, batches of clotting factor concentrate were manufactured from pooled donations of blood, potentially mixing blood products from thousands of donors. This placed a heavy demand on blood supplies and also greatly increased the risk of contamination. Because of local shortages of clotting concentrate, the UK imported supplies derived from paid–for blood donations in the United States. In some cases, these may have been sourced from groups at high risk of carrying hepatitis C/HIV.

A January 2017 <u>plenary debate</u> highlighted that 273 patients in Wales acquired HIV or hepatitis C through contaminated blood/blood products, and 70 of these people have died as a result.

#### Financial support

Responding to that debate, the Cabinet Secretary for Health, Well-being and Sport highlighted work underway to reform the system of financial support provided by the Welsh Government to those affected by hepatitis C and HIV through treatment with contaminated blood. He said:

We would have preferred to have done this on a consistent UK-wide basis, but this is where we are. The five infection-specific schemes established since 1988 have evolved in an ad hoc manner, and over time the system has become complex.

In March 2017, the Cabinet Secretary announced the <u>new support arrangements</u> for affected individuals and their families – 'a single streamlined scheme for Wales to be administered by Velindre NHS Trust through the NHS Wales Shared Services Partnership'.

In his response to the Petitions Committee (August 2018), the Cabinet Secretary said:

Whilst it remains an important consideration that beneficiaries in Wales are not significantly financially worse off than those elsewhere in the UK, the Welsh Infected Blood Support Scheme (WIBSS) does, however, offer a more balanced package of overall support to its beneficiaries compared to that available through some of the other UK schemes.

My officials are currently considering a number of options for overall scheme benefits for 2018–19 that are fair, transparent and offer the best overall package of support within the available resources. One of these options could be to adopt a similar approach to England in relation to Special Category Mechanism but while this work is in progress it is not yet possible to offer you a clear answer on this.

#### **UK Infected Blood Inquiry**

A key development to be aware of is the independent public <u>Inquiry into the use of infected blood</u>, chaired by Sir Brian Langstaff, which is now underway. Preliminary hearings are taking place towards the end of September.

The Inquiry's <u>terms of reference</u> include consideration of the nature and adequacy of the treatment, care and support (including financial assistance) provided to people who were infected and affected, including the extent of any differences in the arrangements made for financial assistance between England, Wales, Scotland and Northern Ireland.

<u>Haemophilia Wales</u>, which campaigns for haemophiliacs infected with contaminated blood products, is a core participant in the Inquiry.