

Witness Name: VAUGHAN GETHING
Statement No: WITN5665001
Exhibits: WITN5665002 - WITN5665006
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF VAUGHAN GETHING

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006, dated 18 November 2020.

I, Vaughan Gething, will say as follows: -

Section 1: Introduction

1. My name is Vaughan Gething, MS, Minister for Health and Social Services for Wales. My date of birth is GRO-C 1974. My work address is Senedd Cymru, Ty Hywel, Cardiff Bay, Cardiff, C99 1NA.
2. In June 2013 I was appointed as the Deputy Minister for Tackling Poverty and in September 2014 I was appointed as Deputy Minister for Health. In May 2016 I was appointed as Cabinet Secretary for Health, Well-being and Sport. In November 2017 I was appointed as Cabinet Secretary for Health and Social Services and in December 2018 I was appointed Minister for Health and Social Services.
3. Professor Chris Jones, Deputy Chief Medical Officer and Catherine Cody, Senior Policy Official within the Welsh Government's Department of Health and Social

Services (DHSS) have been involved in providing advice and information to me in respect of the issues set out below.

Section 2: Alleviating the suffering of those infected and affected by infected blood and blood products

4. From 1988 ex-gratia support for those infected and or affected by Hepatitis C and/or HIV following receipt of infected blood or blood products that occurred in the 1970s and 1980s was provided through what was commonly known as the “Alliance House” schemes. These were the Eileen Trust, McFarlane Trust, MFET Ltd, Skipton Fund and the Caxton Foundation, which were set up by, and administered by the UK Government. The process of devolving powers from Westminster to Wales, Scotland and Northern Ireland, including those in relation to health, gained momentum from 1999 onwards. In 2016 the UK Government decided that this support should be the responsibility of each of the devolved administrations.
5. In October 2016 (when I was the Cabinet Secretary for Health, Well-being and Sport) I wrote to the 280 people who had been infected in Wales, and were at that time being supported through the “Alliance House” schemes. I invited those individuals to complete a short survey of their views about how available funding could best be used to assist them in everyday living and planning for the future. All were invited to contribute their views in writing as well as attending workshops led by officials. Having received those contributions and after stakeholder sessions, officials produced a summary report of these responses [WITN5665002].
6. Following this work, officials developed a new scheme which reflected the requirements of those individuals. On 30 March 2017, I announced that the Welsh Government would be introducing new support arrangements for individuals and their families affected by hepatitis C and HIV through treatment with contaminated blood in Wales. These arrangements would be administered through a new process which would become operational in October 2017. These arrangements are known as the Wales Infected Blood Support Scheme (WIBSS). I attach at [CVHB0000040]

a copy of my Written Statement that was issued at the time, which explains the development and content of WIBSS in greater detail.

7. WIBSS provides financial support and advisory services to those affected by hepatitis C (HCV) and/or HIV as a result of receiving infected blood/blood products through NHS treatment in Wales. When the scheme came into being in October 2017, we made backdated payments to those covered by our scheme for the whole of the 2016/17 financial year in line with the rates paid to those on the England Infected Blood Support Scheme (EIBSS). Annual rises have been awarded to the WIBSS ex gratia payments in line with inflation.
8. In Wales, Velindre NHS Trust is responsible for the function of managing and administering WIBSS. The Welsh Ministers, exercising powers under the National Health Service (Wales) Act 2006, issue directions to Velindre NHS Trust in relation to the management and administration of WIBSS. To date, WIBSS has been funded by Welsh Ministers with some funding received from the UK Government for payments relating to individuals with HIV.
9. On 6 March 2019 I issued a further Written Statement [WITN4065002] which confirmed that WIBSS would be providing enhanced support to beneficiaries. In particular, I announced that an enhanced payment (known as 'Enhanced Hep C Stage 1+') would be available to those with existing Stage 1 hepatitis C who were suffering from mental health symptoms. This enhanced support was added to WIBSS from 1 April 2018 and also includes a structured assessment and personalised package of additional assistance to be offered to all those infected and their families as part of the new WIBSS psychological support arrangements.

Support for the Bereaved provided by WIBSS since 2017

10. In the event of a death of a beneficiary under WIBSS, the scheme offers both a £10,000 bereavement payment, plus the continuation of beneficiary entitlement for three years from date of death, at a rate of 75%.

11. Any ongoing payment entitlement, is calculated from the date of death of the beneficiary and payments are made pro rata dependent on when WIBSS are notified of the beneficiary's death. In the event that a WIBSS beneficiary dies where at the time of their death, they have no surviving spouse or partner, the entitlement to the bereavement payment and further three years of support may be paid to their dependent children. To be a dependent child, at the date of death of the beneficiary, you must be an individual under the age of 18, or under the age of 21 if you are in full time education. In addition, if there is more than one dependent child, any payment received can be paid to each qualifying individual in equal shares.

Psychological Support

12. As set out in my Written Statement dated 6 March 2019 [WITN4065002], I confirmed that the Welsh Government would be providing additional on-going funding of £75k per annum to WIBSS to enable them to set up and run a bespoke psychological support service.

13. This service went live in January 2020, allowing individuals registered with WIBSS, their family members and bereaved family members to access psychological assessment and treatment around the emotional difficulties of being given and living with a diagnosis of Hepatitis C and/or HIV. This specialist team are aware of the historical context and have experience of working with the emotional difficulties that have occurred as a result. It is hoped that by offering a specialist psychology service there will be some acknowledgement and recognition of the physical and psychological complexity, and the impact on quality of life and relationships.

14. The service is available either over the telephone, face to face or via electronic meeting packages. The team are able to travel to visit beneficiaries if required. There is no financial limits on the number of appointments or contacts on offer.

15. In Wales, we have been guided by our beneficiaries under WIBSS as to their requirements. We have as far as we have been able to accommodate these requirements, within the financial envelope available to us and within the Welsh Government's budget.

16. Following our initial stakeholder engagement in 2016 it was evident that in addition to the main elements of the scheme, assistance for widows was required and we included an element for this in our scheme. In Wales we provide a holistic wrap around service of the following; welfare benefits advice, debt counselling, and assistance with form filling, help accessing health services and attendance at benefit assessments. All of these are available to beneficiaries and their families.

17. Following the inclusion of the Special Case Mechanism (SCM – support for those with Hep C stage 1 with additional needs) in England (December 2017) we worked with our beneficiaries to devise our Hep C+ scheme which differs in that we have a simpler application process and no medical input is required. At the same time WIBSS was the first scheme to introduce ongoing bespoke psychological services which are open to all our beneficiaries, their families and the bereaved. Following a self-referral to the psychology team, an assessment appointment will be offered which will be an opportunity to talk through the previous and current emotional difficulties and consider options for treatment going forward. The psychology team are able to offer a telephone conversation before and after referral if there are any questions or concerns about what to expect from a psychology assessment and/or treatment.

18. Welsh Ministers have not matched the increase in ex gratia payments announced by the UK Government on the opening day of the Infected Blood Inquiry in 2019. Officials have been working hard to address the range of parity issues (ex-gratia payments and wrap around services) with their counterparts in the other UK health departments. A bid on behalf of all 4 health departments has been put to UK Treasury by the Cabinet Office.

a. What you understand those differences to be.

19. It is for the other nations and their health departments to explain the nuances of their schemes. However broadly speaking I understand the differences to be as follows:

- Bereavement: WIBSS, along with the schemes in Northern Ireland and England pay a £10k bereavement lump sum. Under WIBSS, Hep C and/or HIV do not have to be detailed on the death certificate as it does under the other schemes. WIBSS also pays 75% of the primary beneficiary's annual payment for 3 years. Scotland make the payment of 100% for the first year and then 75% for life. England and Northern Ireland do not have equivalent payments.
- Hep C+: WIBSS, along with the schemes in England and Scotland have similar category schemes. In Wales we self-assess and no medical evidence is required.
- Hep C lump sum payments: WIBSS, along with the schemes in England and Northern Ireland, pay £20K at stage 1 and £50K at stage 2, whereas in Scotland this is reversed.
- Psychological support: WIBSS offers on-going bespoke help to beneficiaries and their loved ones. Northern Ireland's scheme offers this for the duration of the IBI. England offers a discretionary grant. Scotland are currently setting up this service.
- Income top-up: In Wales we do not offer this other than to those who transferred from the "Alliance House" schemes and were already in receipt of this award. Northern Ireland and England offer this to bereaved spouses. Scotland offer this if required.

b. Whether and if so on what basis, you consider these differences to be justified for the individuals concerned.

20. I would reiterate that we have been guided by our beneficiaries when setting up WIBSS and have accommodated their requests as much as we can. Devolution has enabled each scheme to reflect the needs of their beneficiaries and tailor their schemes accordingly. In Wales we have a holistic wrap around service which looks after the whole person and their families. I believe that our financial package reflects the funding available to us.

c. Next steps to address differences

21. Officials have been working hard, as an interim step in advance of any recommendations by the Infected Blood Inquiry, to draft a policy for Ministerial agreement which aims to ensure greater parity in financial and non-financial

support across the UK schemes, taking account of local circumstances and beneficiaries' needs.

22. My colleague Julie Morgan, MS, the Deputy Minister for Health and Social Services (appointed in December 2018) has been a long standing campaigner for those infected and/or affected to be listened to and to receive answers to their questions. Until her appointment as my Deputy, Julie chaired our Cross Party Group on Haemophilia and Contaminated Blood. Ms Morgan, along with officials took part in a 4 nations Minister's call on 19 July 2019, when parity was discussed. The minutes of this meeting are attached at [WITN5665003]. Both myself and Julie wrote to Caroline Dinenage, MP on 9 October 2019 [WITN5665004] further requesting the funding necessary to enable Wales to work towards parity in the support provided to those infected/and or affected across the UK. Officials have continued to chase for a meeting date but at the time of writing this has not been provided.

23. The Paymaster General, Penny Mordaunt, MP, on behalf of the 4 UK Health Departments and through the Cabinet Office co-ordinated a bid to the UK Treasury to fund the revised UK scheme in late summer 2020. The Welsh Government did not have sight of the final bid that went forward. The document [WITN5665005] is a copy of correspondence dated 13 July 2020 that was sent from Rt Hon Penny Mordaunt MP, to the Chancellor of the Exchequer.

Section 3: Amendments following UK Parity Announcement on 25 March 2021

24. At the regular meeting on 11 March 2021 between the Secretary of State for Health with Health Ministers of the devolved governments, the Secretary of State proposed that the national infected blood support schemes move to a position of broad parity, subject to costings and financial agreement. Ministers from all 4 Nations agreed that we should aim for parity, and that we should work for a solution before the pre-election period.

25. Following a series of discussions at official level I was able to lay a written statement in the Senedd on 25 March 2021 detailing changes to the scheme. These changes address many of the differences in ex-gratia payment rates across the schemes

while retaining the tailored requirements of our WIBSS beneficiaries as requested when setting up the scheme. It is our aim to make these payments to our WIBSS beneficiaries in the coming months in line with the other support schemes

26. I have attached a copy of my Written Statement [WITN5665006].

Section 4: Clinical treatment of those infected

27. Each Health Board in Wales (with the exception of Powys Teaching Health Board) has a specialist blood borne viral hepatitis treatment service. These specialist teams are generally made up of a variety of consultants, clinical nurse specialists, pharmacists and administrative support to deliver high standard treatment and follow-up to all patients identified with HCV infection irrespective of transmission route. The teams also form part of a national network providing advice and guidance and supporting equity of provision. Residents in Powys with HCV infection are referred to neighbouring Health Board teams. During the current Covid-19 pandemic, service provision in these clinical areas has been compromised although the Wales national network of consultants in this area are developing recovery plans for these services.

28. The Welsh Government provides funding to allow HCV treatment via the Health Boards. There is equitable and transparent access to treatment across Wales. Treatment is available for all patients and there are no current funding restrictions.

29. Here in Wales, patients with such conditions such as liver failure, and/or hepatocellular carcinoma, oesophageal varices/variceal haemorrhage, significant fibrosis or cirrhosis would be under the care of a hepatologist or gastroenterologist and would have individual clinical risk assessments to inform further management taking into consideration patient wishes.

Section 5: Identifying those who may be infected

30. I am aware that the Welsh Blood Service (WBS) took part in a Government led 'look back' exercise in 1995, before the establishment of the Welsh Government. I understand that the WBS fed their findings directly back to the Department of Health. There are no current plans to undertake a further look-back/education exercise. Our clinicians are aware of WIBSS and continue to refer patients to that scheme as appropriate. Our HCV patients are managed via a hepatologist or gastroenterologist and they receive care appropriate to their needs.

Section 6: Other

31. I have no further information to add which is relevant to the Inquiry's Terms of Reference.

Statement of Truth

I believe that the facts stated in this witness statement are true.

GRO-C

Signed _____

23 April 2021

Dated _____

Table of exhibits:

Date	Notes/ Description	Exhibit number
March 2017	Welsh Government Survey Responses	WITN5665002
March 2017	Minister's Written Statement Contaminated Blood Reform	CVHB0000040
March 2019	Minister's Written Statement WIBSS Enhanced Support	WITN4065002
July 2019	Readout 4 nations Ministerial call	WITN5665003
October 2019	Minister & Deputy Minister letter to Cabinet Office re Parity	WITN5665004
July 2020	PMG letter to Chancellor re IBI Parity	WITN5665005
March 2021	Minister's Written Statement Update on financial parity	WITN5665006