Witness Name: Professor Chris Jones
Statement No.: WITN4065009
Dated: 31 October 2022

# INFECTED BLOOD INQUIRY

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## WRITTEN STATEMENT OF PROFESSOR CHRIS JONES ON BEHALF OF THE WELSH GOVERNMENT

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 September 2022

Catherine Cody, Senior Policy Official within the Welsh Government's Department of Health and Social Services (DHSS) has been involved in providing advice and information to me in respect of the issues set out below.

I, Prof Chris Jones, will say as follows: -

### Section 1: Ongoing Liver Care

1. I can confirm that the arrangements for follow up of patients with cirrhosis remain as previously described in my statement WITN4065001.

2. I can also confirm that there continues to be no waiting lists for treatment of HCV in Wales.

### Section 2: Palliative Care

3. We want access to palliative and end of life care for all conditions not just advanced liver disease to be underpinned by equity and are working to develop active measures to identify and reduce those evidenced inequities including diagnosis, mental health,

dementia, age, geography, ethnicity, sexual and gender identity, and poverty. In addition, work is also ongoing to review the funding of palliative and end of life care services across Wales. This review is encompassing the whole spectrum of end of life care services, including statutory and voluntary, specialist and generalist and the full age spectrum of children, young people, and adults.

4. Our published (7 October 2022) (https://gov.wales/quality-statement-palliative-and-end-life-care) quality statement for palliative and end of life care sets out the high level Welsh Government policy intention for palliative and end of life care for all conditions including advanced liver disease. Actions include focusing on timely, person centred care from the point of diagnosis or recognition that people are dying, reflecting current knowledge, standards, and guidance to maintain as good a quality life as possible. Work is also ongoing to agree national outcomes and experience measures for people requiring palliative or end of life care and where appropriate, for those close to them, that will be utilised to ensure that people's self-reported experience is driving forward improvements in patient care.

5. I have no additional comments to make on the Inquiries Terms of Reference arising from the evidence of the expert group.

## **Section 3: Psychological Support**

6. To date, over 80 people have accessed the specialist psychological services at the Wales Infected Blood Support Scheme (WIBSS). The split between those infected and affected who have accessed the service is 49% infected and 51% affected. The current caseload is 34.

7. The work is predominantly trauma-led and complex, compounded by and directly attributed to the ongoing Inquiry proceedings and the publication of the Compensation Framework. These events keep members grounded within their past traumatic experiences, where they constantly relive their trauma, keeping it perpetually live and present.

8. Preparatory therapeutic work has also begun around managing the expectation of the Inquiry outcome for individuals and the potential added impact of this on psychological wellbeing to build resilience (realistic versus unrealistic expectation and how this will impact on the ability to move forward after the Inquiry). This work will need to continue once the Inquiry proceedings cease.

9. Following a virtual focus group in February this year members were offered the opportunity to shape a wellbeing service that would meet their needs. Members have been contacted and asked to express their interest in new developments to the service which include:
   - A 'buddy' scheme where members can be put in touch with other members with the aim of reducing isolation through befriending and peer support
   - Regional social events
   - Regional workshop events
   - Regular virtual meetings facilitated by the counsellor, where the agenda is set by attending members.

10. The WIBBS has created an Infected Blood Psychology Network to share best practice, information, and common themes with potential opportunities to work together cross-border with the other UK support schemes. The Network are also discussing published research around the cognitive impact of Hep C with the aim of creating a common assessment framework to assess those members who present with cognitive impairment.

## Section 4: Patient Advocacy

11. The NHS in Wales does not have anyone with the formal title of advocate, but we have people in roles at national level such as the national clinical lead for end of life and our advance care planning lead who could be considered advocates and at local (health board) level too.

12. We currently also have a network of Community Health Councils (CHCs) which operate within each health board area. They provide free confidential advice and support (advocacy) to patients who have a complaint about NHS services. They can provide

support to patients to find relevant information, write letters and attend meetings about their complaint. If a patient is unhappy with the final response provided by the NHS they can support with taking their complaint to the Public Services Ombudsman for Wales (PSOW).

13. From April 2023 a new national body, the Citizens Voice Body for Health and Social Services (CVB), will be created, replacing the CHCs. The CVBs primary purpose is to represent the interests of the public in respect of health and social services. The CVB will continue to offer and strengthen complaints support and complaints advocacy services for health (and social services).

**<u>Statement of Truth</u>**

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

Signed GRO-C

Dated 31 October 2022