



Cynllun Cynorthwyo Gwaed
Heintiedig Cymru

Wales Infected Blood
Support Scheme

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EIN CYFEIRNOD / OUR REF:

DYDDIAD / DATE: 14th November 2019

Mr Thomas Powell
Senior Inquiry Lawyer
Infected Blood Inquiry
Fleetbank House
1st Floor, 2-6 Salisbury Square
London
EC4Y

Dear Mr. Powell,

Request for the production of further information under Rule 9(2) of the Inquiry Rules 2006.

I refer to your letter dated 29th October 2019 seeking additional information. In response to your request, I have replicated all the questions below with our response underneath each. As this letter and the attachments contain person identifiable information both the letter and attachments are sent via the "Egress" secure file sharing portal.

A – Appeals

[In Andy Butler's response dated 14 May 2019, he refers to the Appeals Panel.](#)

i) [Please give the names, titles and qualifications of the appeals panel members. Please also provide a brief overview of their relevant experience.](#)

I have attached a copy of the Wales Infected Blood Support Scheme (WIBSS) Appeals Panel Process for your information. It needs to be updated, to insert reference to the Schedule and paragraph of the WIBSS Directions, as this was inadvertently missed out of the original Directions. It will be included in the Directions when Welsh Government next amends them.

The process has, however, been formally adopted by the WIBSS Governance Group.

The Appeals Panel consist of the following membership. Not all members are required to convene a panel, but the Chair would always be involved along with at least one additional medical representative and a lay representative. The panel held on 16th November 2018 comprised of the Chair, Dr Ch'ng, Dr Srivastava and GRO-A

Andrew Yeoman – Chair

Qualified in 1998 from UWCM. Began GI and Hepatology Training in 2002. Fellowships in New Zealand 2005 and Kings London 2007-2009. Successfully undertook MD in Autoimmune Liver Disease 2016. Consultant Hepatologist in ABUHB since 2010. National Clinical Lead for Liver Disease Delivery Plan in Wales since 2016



Dr Chin Lye Ch'ng, MB BCH BAO, FRCP

Consultant physician since 2004 and has been treating patients with hepatitis C since 1999 having diagnosed first patient in 1991. Currently a consultant physician with special interest in liver disease based in Singleton Hospital. He is BBV Clinical Lead for Swansea Bay Health Board and Hepatology Specialty Lead for Wales to NIHR. He was the Chair of the Treatment and Care Pathway Subgroup, BBV Action Plan for Wales from 2010 to 2015.

Dr Brijesh Srivastava MD FRCP

Dr Brijesh Srivastava is a consultant Hepatologist and clinical lead for Liver services at University Hospital of Wales, Cardiff. He is a member of the national liver disease implementation group in Wales. Brijesh completed his specialist liver training and research at Addenbrooke's Hospital, Cambridge and has been a consultant in Cardiff since November 2015.

GRO-A Patient Representative

Mr **GRO-A** (BSc) is a senior manager in the NHS and a Fellow of the Royal College of Speech and Language Therapists. He has severe Haemophilia B and was infected with Hepatitis C through contaminated blood products during his childhood. He had a series of unsuccessful interferon based treatments but eventually cleared the Hep C virus in 2016 using a combination of Viekirax and Exviera. He has been writing to MPs and AMs since the early 1990's in order to gain support and recognition for those affected by the contaminated blood tragedy. As a patient representative on the All Wales Advisory group, **GRO-A** has worked consistently on behalf of patients across Wales for continued improvements in both service provision and access to new Haemophilia and Hep C treatments.

Helen Cook, Social Worker UHW Lay Representative

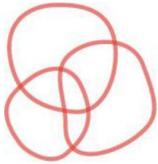
We are still awaiting confirmation of the accuracy of the pen picture from this member and will forward once received.

GRO-A Patient Representative

GRO-A has an Honours degree and a Masters in Humanities, with a professional background in recruitment, and later in Mental Health. He has lived all his life with haemophilia, and was infected with HIV and Hepatitis C in the early 1980s, being diagnosed with the former in 1985 and the latter in 1992. He worked on a voluntary basis for two AIDS support organisations from 1993 to 2002. These were **GRO-A** an organisation established and ran by HIV+ haemophiliacs, based in **GRO-A** but operating throughout the UK, providing support and information, as well as campaigning for better services for its client base, and **GRO-A** based support group for people infected with HIV. His work with these two groups, in addition to his own experience of living with HIV and HCV, helped him to understand the complex physical and psychological needs of people infected and affected by these viruses, and in his own words 'has given me the confidence to participate in the WIBSS appeals panel'.

ii) [Please provide the minutes of all meetings convened by the Appeals Panel since 1 October 2017 where applications are discussed.](#)

There has only been one appeal panel since 1 October 2017. The Appeal Panel convened on 16th November 2018 and considered three appeals.



The documentation for all three appellants was sent to you under cover of Mr Riley's letter dated 16th January 2019. One appeal was successful at the panel meeting. The other two appeals were unsuccessful. However, the Panel members agreed they would reconsider the cases if additional information were submitted. Further details were included in Mr Riley's response dated 16th January. For ease of reference, updated documents for all appellants have been attached.

NAME	FILE NAME(S)
*REDACTED	.pdf
*REDACTED	GRO-A .pdf
*REDACTED	.pdf

iii) If no minutes are kept of these meetings, how are discussions between panel members about the merits of an application recorded?

No formal minutes of the appeals panel are kept, but the panel Chair, on the cover sheet provided with the Appeals Panel pack records a summary of discussions. Copies of the cover sheet are included in the files listed above.

iv) Are earlier decisions of the Medical Assessors and Appeals Panel considered in determining cases with a similar set of facts/claims? Is guidance updated to reflect changing interpretation of the schemes policy?

To date we have only had one Appeals Panel, so there were no earlier decisions by an Appeals Panel to consider in that particular instance. The decisions of the Appeal Panel to date have been considered when determining cases with similar facts since.

Although we do not have a formal panel of Medical Assessors in Wales, we do have access to medical professionals we can contact for an opinion where necessary. Where an opinion has previously been sought, this would be taken into account when considering an application of a similar nature for approval.

Where applicable, the guidance may be changed to reflect changing interpretation of the scheme policy. This has not been required to date, but any future changes would be discussed with the WIBSS Governance Group before being formally adopted. Any changes to scheme policy would need to be made by Welsh Government.

v) What is the appeals procedure for non-medically based applications, such as discretionary grants and income top-up?

WIBSS does not have an appeals procedure for non-medically based applications, such as discretionary grants and income top-up. WIBSS does not currently offer income top-up.

B. New WIBSS Guidance Document

In Andy Butler's response dated 14 May 2019, he refers to ongoing discussions between the Welsh Government and Welsh Blood Service with the aim of creating a new WIBSS Staff Guidance document completely relevant to Wales as opposed to the existing which has been adapted from the Scottish scheme.

- i) Please provide a copy of this document or draft document, if available, or a timeframe for when this guidance will be developed.



The revised documentation has now been completed, and was formally adopted by the WIBSS Governance Group on 5th June 2019. A copy is attached.

C. Enhanced Hepatitis Stage 1+ Payments

In Andy Butler's response dated 14 May 2019, he advised that the Scheme has recently introduced a new payment called Enhanced Hepatitis Stage 1 payment. He explained this payment is a simplified version of the Special Category Mechanism available to beneficiaries in England. In an earlier response from Martin Riley dated 23 November 2018 at part **2.B (d)**, he advised that the new payment would include a "*Mental Health Wellbeing Impact Evaluation*".

i) Please provide a narrative explaining how this policy was developed, and explain whether the Scheme received any expert medical evidence, consulted the beneficiary community or the other devolved schemes in setting up this payment. Did the scheme receive any other external advice?

Welsh Government developed the policy; therefore, this part of the question would need to be directed to the Welsh Government lead, Catherine Cody - Catherine.Cody@GRO-C. I have however attached a copy of the Minister for Health and Social Services' statement announcing the enhanced support, which sets out how the scheme will operate.

ii) Please describe the requirements for this new payment and provide a copy of any updated policy and guidance.

The Enhanced Payment Scheme is for those beneficiaries with Chronic Hepatitis C (Stage 1) infection, who are experiencing significant mental health issues or post-traumatic stress (PTS). It also includes beneficiaries who have HIV and Hepatitis Stage 1 infection.

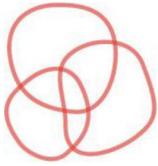
The scheme requires no additional medical input into the application process. Beneficiaries are simply asked if they are suffering from any mental health issues or post-traumatic stress; whether they feel these issues are related to their infection from contaminated blood or blood products; and whether the symptoms are affecting their ability to carry out day-to-day activities. If the answer to these questions is yes, there is no need for further assessment because the person has already been confirmed as diagnosed with Hepatitis C infection from infected blood or blood products.

As part of confirming that they are affected in the way described, they agree to be contacted by the new WIBSS psychology team, who will offer any psychology support as appropriate to the needs of the individual.

Payments for those beneficiaries who meet the requirements increased from £4,622 per annum to the current rate for those with Advanced Hepatitis (Stage 2) infection, which was £18,500 per annum. This was based on the 2018/19 rates.

Applications for the enhanced payment scheme, received by the 23 April 2019 received the higher rate backdated to 1st April 2018. Applications received after that date receive the higher rate with effect from the date the application was received by WIBSS.

Three applications were received by WIBSS within a short time after the 23 April deadline. These were considered on a case-by-case basis, as there were extenuating circumstances why the deadline had been missed; the WIBSS Manager sought approval of the Governance Group to pay the backdated payment. The Governance Group sanctioned this on 5th June.



iii) Please provide a selection of 10 applications for the enhanced payment that have been approved, and any that have been refused and appealed.

The following 10 approved Stage 1+ applications have been randomly selected. No applications were rejected, and therefore there have been no appeals.

NAME	FILE NAME(S)
*REDACTED	.pdf
*REDACTED	GRO-A .pdf
*REDACTED	.pdf
*REDACTED	.pdf
*REDACTED	.pdf
*REDACTED	.pdf
*REDACTED	.pdf

*Names a redacted on covering letter, but information provided through secure EGRESS portal has not been redacted.

D. Approved Stage 1 Applications

i) Please provide **full unredacted** copies of all new applications of Hepatitis Stage 1 payments received after 1 October 2017 that have been approved, including all material considered by the decision maker;

Unredacted copies of all new Hepatitis C Stage 1 applications received between 1 October 2017 and 14th May 2019 have previously been sent to you under cover of Martin Riley's response dated 16th January 2019 and Andy Butler's response of 14th May. Since then we have received three additional Hepatitis C Stage 1 successful applications. Full **unredacted** copies of these have been attached to this letter.

ii) Please ensure each beneficiary file is individually scanned.

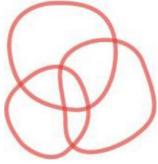
New applications are listed below.

NAME	FILE NAME(S)
*REDACTED	.pdf
*REDACTED	GRO-A .pdf
*REDACTED	.pdf

*Names a redacted on covering letter, but information provided through secure EGRESS portal has not been redacted.

If you require any further clarification or information, please contact me.

Yours sincerely,



Cynllun Cynorthwyo Gwaed
Heintiedig Cymru

Wales Infected Blood
Support Scheme

GRO-C

Alison Ramsey (nee Phillips)
Deputy Director of Finance & Corporate Services
NHS Wales Shared Services Partnership

4/5 Cwrt Charnwood 4/5 Charnwood Court
Heol Billingsley Heol Billingsley
Parc Nantgarw Parc Nantgarw
Caerdydd Cardiff
CF15 7QZ CF15 7QZ

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