

Witness Name: Caroline Lamb

Statement No.: WITN7458050

Exhibits:

Dated: 21st February 2024

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CAROLINE LAMB

I provide this statement in response to a request under Rule 9(1) and (2) of the Inquiry Rules 2006 dated 8 February 2024.

I, Caroline Lamb, will say as follows: -

Access to recombinant blood products for children with Von Willebrand Disease (VWD)

- 1. Please explain NHS Scotland's position on the issue of access to recombinant blood products for children with VWD, setting out the status of any ongoing reviews and next steps.**

Generally patients in Scotland with inherited bleeding disorders, including von Willebrand disease (VWD), are offered access to recombinant factor products where treatment with some form of factor concentrate product is needed to treat their condition.

Few children with VWD need treatment with von Willbrand factor concentrate, as alternative treatments will generally be more appropriate for them. However, they can be offered recombinant products where their clinician and Health Board feel that is most appropriate for them. The recombinant medicine Veyvondi has a UK marketing authorisation from the MHRA for the 'prevention and treatment of haemorrhage or surgical bleeding in adults (age 18 years and older) with VWD, when desmopressin (DDAVP) treatment alone is ineffective or contraindicated'.

Therefore, while Veyvondi is occasionally used for children in Scotland, such use is 'off-label' as the product does not have a marketing authorisation for use for children.

While I understand that there has so far been limited need to consider using Veyvondi in children in Scotland, clinicians can submit a request for individual patient access to the relevant Health Board's local medicine governance process if they do have a child under 18 years old where they feel Veyvondi is the best treatment option.

The Scottish Government is liaising with the Scottish Inherited Bleeding Disorders Network (a managed clinical network) and NHS National Services Scotland's National Services Division (NSD) to ensure consistent guidance for haemophilia centres and Health Boards on use of this product for children. The Scottish Government is therefore seeking expert advice on this matter.

Statement of Truth

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

Signed _____

GRO-C

Dated __21st February 2024_____