Vaughan Gething AC/AM Y Gweinidog lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services



Ein cyf/Our ref: MA-P-VG-2535-19

Angela Burns AM
National Assembly for Wales
Cardiff Bay
Cardiff
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9 July 2019

Dear Angela,

I am writing to you in relation to the comments you raised during health questions on the 3 July 2019 about the current process regarding access to corneal cross linking treatment in Wales.

The "Bridgend Clinic" is a private health-care unit on the Princess of Wales Hospital site. This "Bridgend Clinic" provides corneal services, including treatment for people with keratoconus. As you are aware, it is a patient's individual decision whether or not to pay for private treatment.

NICE does not recommend that Corneal Cross Linking (CXL) should be routinely provided for use in NHS Wales; however, NICE did publish Interventional Procedure Guidance (IPG466)' to assess if CXL is safe and effective. The IPG simply states 'current evidence on the safety and efficacy of epithelium off CXL for keratoconus and keratectasia is adequate in quality and quantity.' As part of the same IPG, NICE also state 'Data on long-term outcomes for all types of corneal CXL using riboflavin and UVA for keratoconus and keratectasia would be useful-specifically data about prevention to progression to corneal transplantation and about repeat procedures and their efficacy'.

In 2018 a Health Technology Wales (HTW) review recommended not to endorse CXL for use in NHS Wales. Whilst the HTW review accepted there were multiple reports about CXL from observational studies, their systematic review concluded the evidence was insufficient in *quality* (rather than *quantity*) to support routine adoption. The main limitation was that the positive conclusion was entirely dependent on an effect which is sustained beyond five years, which has not been definitively demonstrated (using robust research methods) by the available evidence. The ongoing trials may yet provide the level of evidence needed, and will be taken into consideration when HTW reviews its appraisal report in May 2020.

Corneal Cross Linking (CXL) is not currently routinely available as a Wales-wide NHS treatment. Swansea Bay University Health Board (SBUHB) took the decision to treat patients and gather data for analysis to feed into the UK trials underway. Patients that meet the criteria in all health board areas are able to access CXL treatment by referral on a case-by-case basis, to SBUHB, or to an appropriate hospital in England. The clinician

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

must make an Individual Patient Funding Request (IPFR) to the health board and treatment is determined by local guidelines.

In the meantime, we await the outcome of the UK trials and the HTW review of its evidence appraisal report in May 2020.

I hope this response helps to clarify the current position and developing evidence base.

Yours sincerely,

Vaughan Gething AC/AM

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Minister for Health and Social Services