Mark Drakeford AC / AM Y Gweinidog lechyd a Gwasanaethau Cymdeithasol Minister for Health and Social Services



Eich cyf/Your ref P-04-460
Ein cyf/Our ref MD/00169/13
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Dea William

Thank you for your letter of 21 March on behalf of Mr Jeremy Deri-Davies regarding his petition about the delivery of specialised medicines through the Welsh Health Specialised Services Committee (WHSSC) and seeking the views of Welsh Government on the issues raised.

I was very sorry to read about Ms Wheate's condition and the difficulties she has experienced in trying to obtain the medicine pegvisomant. I am aware that Mr Deri-Davies has made previous representations to Welsh Government on this matter

In determining the potential benefit of a medicine such as pegvisomant the Welsh Government is guided by advice from the All Wales Medicines Strategy Group (AWMSG) when the medicine has not been appraised by the National Institute for Health and Clinical Excellence (NICE). The AWMSG carried out an appraisal of pegvisomant in 2005 and recommended it should not be routinely available for use within NHS Wales. In advising the manufacturer of this decision, AWMSG invited the company to submit further clinical data for reappraisal. To date this has not occurred although I am aware that AWMSG have recently had discussions with the manufacturer regarding a possible reappraisal.

The Scottish Medicine Consortium (SMC) also appraised pegvisomant in 2005 and came to a similar conclusion to AWMSG. The manufacturer chose to make a resubmission to SMC in 2006 but SMC again did not recommend pegvisomant for use in NHS Scotland.

The AWMSG is recognised as having a transparent and robust appraisal process. Membership is drawn from across NHS Wales and includes senior clinicians from both hospitals and general practice, nurses, public health clinicians, pharmacists, patients and health economists. More information can be found on the AWMSG website including details of forthcoming meetings, all of which are open to the public and have been since the Group was established in 2002. A link to the AWMSG website can be found below:

http://www.wales.nhs.uk/sites3/home.cfm?orgid=371

The funding of many treatments for rare diseases currently falls under the remit of WHSSC. WHSSC was established in 2010 and is responsible for the joint planning of Specialist and Tertiary Services on behalf of Health Boards (HBs) in Wales. When making funding decisions WHSSC are also guided by advice from AWMSG but may also consider advice from their Individual Patient Funding Request (IPFR) panel where the patient may fall outside current AWMSG, or NICE, guidance.

In your letter you also make reference to the high cost of medicines. The pricing of medicines is a non-devolved issue but ensures the NHS has access to quality branded medicines at reasonable prices. The price of medicines in the UK is now one of the lowest in Europe and we strive to drive down costs further, particularly in hospitals, by having all-Wales contracts in place for selected medicines. In addition, and since 2011, we have also operated a scheme which provides, high cost, AWMSG approved medicines at an additional discount to the NHS.

I hope you have found this information helpful.

Bost work.

Mark Drakeford AC / AM

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