THE HON NICOLA ROXON MP
MINISTER FOR HEALTH AND AGEING

RECEIVED
29 OCT 2010
340/601
PETITIONS COMMITTEE

The Chair
Standing Committee on Petitions
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Chair

I refer to a letter of 22 June 2010 from the then Chair of the Standing Committee on Petitions, Mrs Julia Irwin, regarding a petition submitted to the Standing Committee on Petitions for the funding of SOLIRIS® (eculizumab) for the treatment of paroxysmal nocturnal haemoglobinuria (PNH) through the Life Saving Drugs Program (LSDP). I apologise for the delay in responding.

The LSDP provides subsidised access for eligible patients to expensive and life saving drugs for serious and rare medical conditions. There are no alternative drugs or suitable therapeutic options for the conditions treated under the LSDP.

The Pharmaceutical Benefits Advisory Committee (PBAC), an independent expert advisory committee, considered a submission for the funding of SOLIRIS through the LSDP in March 2009. While the PBAC did recommend that SOLIRIS be considered by the Australian Government for inclusion on the LSDP, it also noted a number of uncertainties in the evidence about the drug. These included doubts on the extent that SOLIRIS extends life compared to best supportive care, and the size of the benefit in reducing the incidence of blood clots, which is a serious component of the disease.

In light of the uncertainty associated with the effectiveness of SOLIRIS, I made an urgent request for further advice from the PBAC on the merits of SOLIRIS being funded through the LSDP.

On 13 August 2010, the PBAC made a recommendation to the Government to consider the funding of SOLIRIS through the LSDP for the treatment of PNH.

Further details on this recommendation are available from my Department's website at www.health.gov.au/internet/main/publishing.nsf/Content/pbac-outcomes-by-meeting

While the PBAC has recommended SOLIRIS for subsidy through the LSDP, there are a number of steps that must be completed before the drug can be considered by the Government. These steps include establishing a Disease Advisory Committee to finalise eligibility and continuation criteria, and funding arrangement negotiations with the sponsor, Alexion Pharmaceuticals.

Parliament House Canberra ACT 2600 • Telephone: (02) 6277 7220 Facsimile: (02) 6273 4146

A PNH Disease Advisory Committee has now been established and will be chaired by Professor Jeffrey Szer.

My Department is working with Professor Szer and the sponsor to progress this work as quickly as possible.

I trust that the above information is of assistance.

Yours sincerely

NICOLA ROXON

28 OCT 2010